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VIETNAMESE FAMILY CAREGIVERS' ADJUSTMENT PROCESS TO THEIR  
CAREGIVING ROLES FOR FAMILY MEMBERS WITH DEMENTIA

by

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Submitted in Partial Fulfillment of the Requirements

For the Degree of Doctor of Philosophy in

Social Work

College of Social Work

University of South Carolina

2019

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## DEDICATION

I dedicate my dissertation work to my beloved family, the dearest friends, and 20 Vietnamese family caregivers who participated in my study. First of all, I would like to express my deepest gratitude and gratefulness to my loving parents, Khoa Duy Nguyen and Lan Ngoc Le, and my most trusted and supportive sister, Tra-My Ngoc Nguyen. They always give me unconditional love and encouragement, support me to pursue my dreams, and never leave my side.

I also dedicate this work to my special friends, Judy and Charlie Beazley, as well as my foster mother, Toshiko Sato. They inspired me to choose my research topic and pursue my goal to become a scholar in resilience of family caregivers in dementia care.

I also dedicate this work to all my dear friends, my cheerleaders, Thao Huong Nguyen, Minh Nguyen, Nguyen Vu and her family, Aya Nance, Hoa Mai Nguyen and her family, Ha Trinh and her husband - Renil Anthony, Emily Arnold and her daughters, and many other friends in Vietnam, United States, and Germany.

I dedicate this work and give special thanks to the 20 Vietnamese family caregivers who participated in my study. My participants once said: *“The voices of dementia caregivers like us have been muted for too long. We believed that your study will help our voices be heard!”* This dissertation, therefore, is to fulfill my commitment to them, with my humility and gratitude for their sharing of wisdom and meaningful life stories in their journeys of dementia care.

## ACKNOWLEDGEMENTS

I wish to thank my committee members who have spent tremendous time guiding me through the dissertation process with their expertise and feedback. First, a special thanks to Dr. Sue Levkoff, my committee chair. Thank you for always making time to answer my questions, discuss my ideas, and push me to think critically on every work I have done in the doctoral program. Thank you for working one-on-one with me and give me your feedback to help me revise my dissertation. It is my honor to have you as my advisor and mentor, and I am very grateful for what I have learned from you.

To Dr. Huong Nguyen, thank you for taking a chance on me when I applied to the doctoral program. In the past five years and even before the doctoral program, you have advised and supported me in many ways, and taught me so much that I could not thank you enough. Both Dr. Levkoff and you contribute to shape the scholar I want to be, and the one I have become. Also, thank you, Dr. Teri Browne and Dr. Thanh Tran for serving on my committee. In addition, I would like to thank Dr. Hongtu Chen and Jim Maxwell for their helpful feedback on my dissertation.

I would like to acknowledge and thank the health professionals and staff at the National Geriatric Hospital in Hanoi, Vietnam for allowing me to recruit participants at the hospital and providing generous assistance during my data collection process.

I also want to thank the Graduate Research Grant “Support to Promote Advancement of Research and Creativity (SPARC)” to support my dissertation work.

## ABSTRACT

This study explores the psychological process that Vietnamese family members go through to adjust to the caregiving role for their relatives with dementia. Adopting constructivist grounded theory, 30 face-to-face, semi-structured interviews, including 10 follow-up interviews, were conducted with 20 Vietnamese primary family caregivers of relatives with dementia from the National Geriatric Hospital in Vietnam. The study results reveal that Vietnamese family caregivers held limited understanding of dementia. They used a mixed explanatory model, combining both folk (e.g., dementia as normal aging) and biomedical approaches (e.g., dementia as a brain-related disease) to explain causes of dementia. Family cohesion and responsibility are highly valued, leading to their decision to voluntarily undertake the role of primary caregiver, and to delay decisions to seek help outside the family, regardless of the multiple burdens they experience.

Most importantly, the data reveal a theory of a transactional model that explains the psychological process through which Vietnamese family caregivers go through as primary caregivers. The transactional model refers to the mutually reciprocal interactions between caregivers and their environment. This model illustrates the core psychological adjustment process as an iterative cycle of four stages (*Experience* of the symptoms and hands-on caregiving activities; *Acknowledgement* of hardship and changes of the self in caregiving; *Experiment* with strategies for providing care to the relative and strategies for self-care; and *Acceptance* of the caregiving situation and role). Caregiver personal factors (demographic and relationship characteristics with care recipients; personal beliefs and

commitments in caregiving; and personal history of caregiving and coping with past adversity) and structural factors (cultural values and norms; social support; and social pressure) interact with each other to impact their psychological adjustment process. By attending to the nexus of individual experiences, cultural context, and the transactional relationship between caregivers and their environments, this research may provide an important new framework for examining the transition into the caregiving role more generally. The specific results regarding the role of the ‘*self*’ in caregiving and acceptance significantly contribute to the existing literature examining the adjustment process of family caregivers. Not only do these results have implications for cross-cultural studies, they can also inform intervention development targeting resilience for diverse family caregivers in a broader context.

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## LIST OF ABBREVIATIONS

AD.....	Alzheimer’s Disease
ADLs.....	Activities of Daily Living
APA.....	American Psychiatric Association
DSM-IV-TR.....	Diagnostic and Statistical Manual of Mental Disorders, 4th Edition
GSO.....	General Statistics Office
IRB.....	Institutional Review Board
MOH .....	Ministry of Health
NGH .....	National Geriatric Hospital
PTSD .....	Post-Traumatic Stress Disorder
UNFPA .....	United Nation Population Fund Vietnam
USC .....	The University of South Carolina

# CHAPTER 1

## INTRODUCTION

The older adult population has been rapidly rising in Vietnam, which makes Vietnam one of the fastest aging countries in the world (Tatarski, 2016; United Nation Population Fund [UNFPA] Vietnam, 2010, 2011). In 2014, the number of people aged 60 and above was approximately 9.5 million, accounting for 10.45% of the total population, and was predicted to go up to 30.8% in 2050 (General Statistics Office & UNFPA, 2016; HelpAge Global Network, n.d.). As a consequence, the burden of providing healthcare for noncommunicable diseases, including dementia, is projected to increase (Bang et al., 2017; Truong, 2015).

Family caregivers often confront many challenges during their care for relatives with dementia. According to Baltes (1996), dementia is one of the most difficult illnesses for family members to cope with. Alzheimer's Disease, which comprises 60% of dementia cases, is shown to have the most serious effects on the affected individuals and their families (Walsh, 1998). Studies address caregivers of older adults with dementia as '*hidden patients*' (Parks & Novielli, 2000) or '*invisible second patients*' (Brodaty & Donkin, 2009; Walsh, 1998). Family caregivers of older adults with dementia often face intense burdens, morbidity, along with physical, psychosocial and financial difficulties that influence not only their life quality but also the life quality of care recipients (Brodaty & Donkin, 2009).

In Vietnam, taking care of older adults, particularly when they are sick, is considered a primary responsibility of the family unit, including both nuclear and extended families. Under the strong influences of Confucianism and Buddhism, taking care of older parents is a moral conduct of filial piety (Truong, 2015). Family responsibility in elder care is found consistently not only in daily practice at the community level (Dam, Tran, Duong, Khuong, & Nguyen, 2009; Truong, 2015), but also in the government policies. According to Chapter 2, Section 1, Article 10 in the Law on the Elderly, children, grandchildren, and other relatives are entitled to the right and duty of collaboration for caregiving for older adults in their families (Vietnam National Assembly, 2010). Taken together, Vietnamese family members assume their primary caregiver role with limited intention to reach out to other resources outside of the family (B. N. Nguyen et al., 2013; Truong, 2015).

Undertaking the main responsibility in dementia care, Vietnamese family caregivers often confront multiple challenges with insufficient social support (B. N. Nguyen et al., 2013; Truong, 2015). Dementia caregivers in a rural area in Northern Vietnam reported four types of caregiving burdens, including their own physical health problems (e.g., fatigue and sleep disturbance), psychological challenges (e.g., overwhelming and anxiety), time and financial constraints (T. B. Nguyen et al., 2018). In addition, the more distressed and disturbed the care recipients became during the course of dementia, the higher burden their family caregivers reported (B. N. Nguyen et al., 2013). Higher perceived burden and lack of confidence in managing behavioral and psychological symptoms of dementia predict low quality of life among caregivers (Truong, 2015).

One of the most critical factors contributing to the lack of confidence in and struggles to managing dementia care is the lack of knowledge of dementia among Vietnamese family caregivers. Studies in a rural area in the North of Vietnam find that family caregivers had not heard of or understood dementia from the biomedical perspective. Instead, they explained dementia as '*being confused*' due to the normal aging process or unspecified reasons (B. N. Nguyen et al., 2018; T. B. Nguyen et al., 2018). Associated with this belief, caregivers assumed that the conditions of the care recipients would remain the same till the end of their lives and seeking medical treatment or learning new caregiving skills would not be necessary. Instead, they practiced care intuitively and tended to struggle to cope with caregiving distress on their own or with informal support from their families and friend circles (B. N. Nguyen et al., 2018). As caregivers are not aware of the progressive course of the disease, their distress is likely to increase as the dementia progresses with more severe symptoms.

Despite the emerging problems in dementia care, Vietnamese family caregivers rarely access to and seek help from the formal healthcare system even when they are available (B. N. Nguyen et al., 2018; T. B. Nguyen et al., 2018). Healthcare services in dementia diagnosis and treatment also appeared extremely sparse at the community level. Even community health workers who were providing services to older adults with dementia had no awareness of dementia and held very limited knowledge or skills regarding dementia care (B. N. Nguyen et al., 2018). Together, the limited existing studies on dementia care in Vietnam suggest that Vietnamese family caregivers face multiple burdens resulting in a high risk of reduced quality of life during the adjustment

process to their caregiving role. Their burdens and adjustment are associated with their perception of dementia and caregiving, as well as their help-seeking patterns.

Despite the fact that taking care of older adults with dementia is intensely challenging in the Vietnamese context, the existing literature exposes a large knowledge gap in how Vietnamese family caregivers adjust to the caregiving role for their relatives with dementia. Particularly, we still do not know how Vietnamese family caregivers perceive dementia and caregiving. More specifically, what explanatory models do they have for making sense of dementia, as these perceptions will likely contribute to their help-seeking behaviors, and impact their ability to cope with the challenges of day-to-day care and the psychological processes they go through to do so. In addition, very little is known about what they perceive as facilitators and inhibitors to their care for their loved ones with dementia. We also lack information of their help-seeking perceptions and behaviors while coping with the challenges of the care duty. Furthermore, we have no knowledge of what psychological processes Vietnamese family caregivers go through to adjust to their caregiving role for relatives with dementia in their particular sociocultural context. Given the chronic and progressive nature of the disease, older adults often suffer from dementia for a long time, leading to recursive adjustment processes of family caregivers.

Addressing the knowledge gaps, this study aims to explore the adjustment process of Vietnamese family caregivers to the caregiving role for their relatives with dementia. In this study, the specific aims are:

- (1) To identify Vietnamese family caregivers' perceptions of dementia and its causes, their caregiving roles, as well as facilitators and barriers to their role as primary caregivers for their relatives with dementia (*Paper 1*).
- (2) To examine help-seeking perceptions and behavioral patterns of Vietnamese family caregivers who provide care for their relatives with dementia (*Paper 2*).
- (3) To explore the psychological processes through which Vietnamese family caregivers adjust to their role as primary caregivers for relatives with dementia (*Paper 3*).

The study contributes not only to filling the knowledge gap of Vietnamese family caregivers in dementia care, but also provides lessons learned about how to select and apply culturally competent research methods, particularly constructivist grounded theory in a cross-cultural context. Grounded theory is one of the most rigorous qualitative methods to explore participants' "*experiences over time or changes that have stages and phases*" (Creswell, Hanson, Plano, & Morales, 2007, p. 239). Based on a search of the literature, my proposed study will be the first using a grounded theory study to increase understanding of the adjustment process for Vietnamese family caregivers who care for older adults with dementia in the Vietnamese context. The results of the study have the potential to set a foundation for other dementia caregiving research.

In addition to the methodological contribution, the study results will yield practical implications for supporting Vietnamese family caregivers in dementia care. As the study addresses Vietnamese family caregivers' experiences and reflects their needs regarding the adjustment process to their caregiver role, its results are significant to the development of interventions and services for family caregivers of older adults with



dementia. Study results will also contribute to policy advocacy targeting family caregivers in the Vietnamese social welfare system. Until now, there has been no policy or social service for family caregivers in the formal social service system in the country. Along with the rise of the social work profession in Vietnam, social work has been identified as the key profession that will contribute to the social welfare system that provides long-term care to support older adults with dementia and their family caregivers (H. Nguyen, 2016). This study, therefore, will contribute to not only methodologically and to the development of social work scholarship, but also to the policy environment, as the findings will help identify needs, barriers, and facilitators to effective support in these underserved populations.

## CHAPTER 2

### PAPER 1: CULTURALLY BASED PERCEPTIONS OF DEMENTIA AND CAREGIVING AMONG VIETNAMESE FAMILY CAREGIVERS<sup>1</sup>

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<sup>1</sup> Nguyen, T. Culturally based perceptions of dementia and caregiving among vietnamese family caregivers. To be submitted to *Journal of Cross-Cultural Gerontology*.

## **Abstract**

This paper explores Vietnamese family caregivers' perceptions of dementia, their caregiving roles, as well as perceived facilitators and barriers to their adjustment to their caregiving roles for their family members with dementia. Using constructivist grounded theory, 30 face-to-face, semi-structured interviews were conducted with 20 primary family caregivers of patients with dementia who had been recruited from a geriatric hospital in Vietnam. Results reveal that Vietnamese family caregivers held ambiguous perceptions of dementia. They referred to dementia as '*being confused*,' '*forgetfulness*,' and '*absent-minded*,' as a consequence of the aging process, physical health conditions, and psychological distress. Their perceived causes of dementia map on the mixed explanatory model, combining folk (e.g., dementia as normal aging) and biomedical approaches (e.g., dementia is a brain-related disease). Caregivers perceived caregiving primarily a family duty that was shaped by their culturally based beliefs rooted in the Confucianism and Buddhism traditions. Adult child caregivers referred to caregiving as a filial responsibility/obligation, while spousal caregivers associated caregiving with affection and gratitude for care recipients. Caregivers revealed facilitators to their caregiving, including care recipients' manageable cognitive condition, their own stable physical health, personal beliefs and commitments to caregiving, and adequate social support available to them. Barriers to caregiving consisted of care recipients' problematic cognitive and behavioral conditions, burdens associated with role demands and conflicts, lack of social support, and social pressure and judgmental attitudes from other family members and community.

## **Keywords**

Dementia; Alzheimer's Disease; Vietnamese family caregivers; perceptions; facilitators; barriers; grounded theory

## **INTRODUCTION**

The older adult population has been rapidly rising in Vietnam which makes Vietnam one of the fastest aging countries in the world (Tatarski, 2016; United Nation Population Fund [UNFPA] Vietnam, 2010, 2011). In 2014, the number of people aged 60 and above was approximately 9.5 million, accounting for 10.45% of the total population, and was predicted to go up to 30.8% in 2050 (General Statistics Office & UNFPA, 2016; HelpAge Global Network, n.d.). As a consequence, the burden of providing healthcare for noncommunicable diseases, including dementia, is projected to increase (Bang et al., 2017; Truong, 2015).

Dementia is one of the most difficult illnesses for family members to cope with (Baltes, 1996). Alzheimer's Disease, which comprises 60% of dementia cases, is shown to have the most serious effects on the affected individuals and their families (Walsh, 1998). Studies address caregivers of older adults with dementia as '*hidden patients*' (Parks & Novielli, 2000) or '*invisible second patients*' (Brodaty & Donkin, 2009; Walsh, 1998). Family caregivers of older adults with dementia often face intense burdens, morbidity, along with physical, psychosocial and financial difficulties, which all influence their quality of life (Brodaty & Donkin, 2009).

In Vietnam, taking care of older adults, particularly when they are sick, is considered a primary responsibility of the family unit, including both nuclear and

extended family. Under the strong influences of Confucianism and Buddhism, taking care of older parents is a moral conduct of filial piety (Truong, 2015). Family responsibility in elder care is found consistently not only in daily practice at the community level (Dam, Tran, Duong, Khuong, & Nguyen, 2009; Truong, 2015), but also in the government policies. According to Chapter 2, Section 1, Article 10 in the Law on the Elderly, children, grandchildren, and other relatives are entitled to the right and duty of collaboration for caregiving for older adults in their families (Vietnam National Assembly, 2010). Taken together, Vietnamese family members assume their primary caregiver role with limited intention to reach out to other resources outside of the family (B. N. Nguyen et al., 2013; Truong, 2015).

Undertaking the main responsibility in dementia care, Vietnamese family caregivers often confront multiple challenges with insufficient social support (B. N. Nguyen et al., 2013; Truong, 2015). Dementia caregivers in a rural area in Northern Vietnam reported four types of caregiving burdens, including their own physical health problems (e.g., fatigue and sleep disturbance), psychological challenges (e.g., overwhelming and anxiety), time and financial constraints (T. B. Nguyen et al., 2018). In addition, the more distressed and disturbed the care recipients became during the course of dementia, the higher burden their family caregivers reported (B. N. Nguyen et al., 2013). Higher perceived burden and lack of confidence in managing behavioral and psychological symptoms of dementia predict low quality of life among caregivers (Truong, 2015).

One of the most critical factors contributing to the lack of confidence in and struggles to managing dementia care is the lack of knowledge of dementia among

Vietnamese family caregivers. Studies in a rural area in the North of Vietnam find that family caregivers had not heard of and or understood dementia from the biomedical perspective. Instead, they explained dementia as '*being confused*' due to the normal aging process or unspecified reasons (B. N. Nguyen et al., 2018; T. B. Nguyen et al., 2018). Associated with this belief, caregivers assumed that seeking medical treatment or learning new caregiving skills would not be necessary because it was just '*normal aging*.' Instead, they practiced care intuitively and tended to struggle to cope with caregiving distress on their own or with informal support from their families and friend circles (B. N. Nguyen et al., 2018). As caregivers were not either aware of the progressive course of the disease, or accessing to formal health care services, their distress is likely to increase as the dementia progresses with more severe symptoms.

Despite the emerging problems in dementia care, Vietnamese family caregivers rarely access to and seek help from the formal healthcare system even when they are available (B. N. Nguyen et al., 2018; T. B. Nguyen et al., 2018). Healthcare services in dementia diagnosis and treatment also appeared extremely sparse at the lower levels, such as commune-, district-, and even provincial levels. Community health workers from commune health clinics who provide services to older adults were found to have no awareness of dementia and very limited knowledge or skills regarding dementia care (B. N. Nguyen et al., 2018). Together, the limited existing studies on dementia care in Vietnam suggest that Vietnamese family caregivers face multiple burdens resulting in a high risk of reduced quality of life during the adjustment process to their caregiving role. Their burdens and adjustment are associated with their perception of dementia and caregiving, as well as their specific caregiving situations. In short, little is known about

perceptions of dementia and available resources for caregiving among Vietnamese people. The existing literature exposes a big knowledge gap in perceptions and experiences of dementia and caregiving, such as help-seeking, among Vietnam family caregivers whose relatives are clinically diagnosed with dementia and receiving medical treatment from the formal healthcare system.

Besides, little is known about how the current context shapes dementia caregiving perception and experiences of Vietnamese family caregivers. Previous studies acknowledge differences in care models for older relatives across geographical regions in Vietnam (Dam, Tran, Duong, & Khuong, 2006; Truong, 2015). Dam et al. (2006) suggested that older adults in the Southern and Central regions of Vietnam tended to live in the same household and receive more attention and direct care from their children and grandchildren, while their counterparts in the Northern region often lived with their spouses and received care from their younger family members only when they were sick. These regional care models may also be in flux due to the rapid industrialization and urbanization in the country (Bang et al., 2017; Dam et al., 2006). The economic trend, job migration patterns from the rural to urban areas contribute to change family structures. Older adults in rural areas tend to live with their spouses and/or small grandchildren only. The potential lack of hands-on care from their older children would change not only the role-taking among family members, but also caregivers' perception of dementia, caregiving role, and associated factors with their caregiving. This situation calls for more studies to further understanding of Vietnamese family caregivers in the new context.

Addressing these important knowledge gaps and assumptions, this paper aims to identify Vietnamese family caregivers' perceptions of dementia, caregiving roles, as well

as facilitators and barriers to their adjustment to caregiving roles for their family members with dementia. As the first of the trilogy, this paper reports results drawn from a larger study that examines the complex caregiving experiences in dementia care of Vietnamese family members recruited from the hospital setting in the North of Vietnam.

This research is important for multiple reasons. By adopting constructivist grounded theory (Charmaz, 1990, 2014), the results of the study have the potential to set a foundation for other dementia caregiving research, given the situation that this study is one of the first using a grounded theory study to increase understanding of the adjustment process for Vietnamese family caregivers who care for older adults with dementia in the Vietnamese context. The study results will also be used to inform practical implications for culturally competent interventions and service development targeting Vietnamese family caregivers in order to support their adjustment to their caregiving role and improve their quality of life, as findings will help identify needs, barriers, and facilitators to effective support in these underserved populations.

## **METHOD**

### **Research design**

This paper reports the results from a constructivist grounded theory study (Charmaz, 1990, 2014). Constructivist grounded theory adopts symbolic interactionist perspective which is suitable for researchers to explore participants' living experiences from their own perspective (Charmaz, 1990, 2014). This approach is also beneficial in studies on health beliefs and caregiving practices considering specific cultural factors, such as caregiving of Vietnamese families in their own context and culture (Carroll et al., 2007; Liu et al., 2014, 2015; McCalman et al., 2013; Mendez-Luck et al., 2016; Ononeze



et al., 2009; Waterworth et al., 2016). Theoretical sampling and constant comparative method were applied during the iterative process of data collection and analysis for theory development (Charmaz, 1990, 2014; Ng & Hase, 2008).

### **Ethical consideration**

The research and interview protocol were accepted by the University of South Carolina (USC) Institutional Review Board (IRB). The Vietnamese IRB form was also submitted to the National Geriatric Hospital (NGH) where the participants were recruited. The Vietnamese informed consent was collected from each participant before their first interviews. The Vietnamese informed consent clearly stated that participants were reserved their right to withdraw from the study at any time of their wish. All identifiable information of participants was removed from transcripts. Each participant was assigned an identification number. All data were stored in a secured folder on a laptop which only the researcher could access with a password.

### **Setting**

Participants were recruited from the National Geriatric Hospital (NGH) in Hanoi, the capital of Vietnam. Most Vietnamese people use healthcare services from public hospitals in the Ministry of Health (MOH) system. The MOH is structured with four-tier hospital system, including precinct-, district-, provincial-, and national levels. Specialized geriatric services merely exist at the precinct and district levels, and only 28/63 provincial-level hospitals operated geriatric departments targeting older adults (H. Nguyen, 2016). When the provincial-level hospitals cannot provide necessary treatments for patients, patients will be referred to the national-level hospitals, such as NGH. Since 2009, NGH has been the only specialized geriatric hospital in the country where provides

services for older adults with severe mental disorders and specialized program in dementia care (H. Nguyen, 2016).

The Dementia Program is utilized under the Department of Neuropsychiatry and Alzheimer's Disease. The health professionals in the department include four psychiatrists, 15 nurses, and a nurse assistant. They provide clinical diagnosis of dementia using Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM IV TR; American Psychiatric Association [APA], 2000), as well as medical treatment for patients. Patients in the Dementia Program are often prescribed with medicines for dementia symptoms, such as Aricept and Razadyne (Galantamine), in addition to supplements, such as vitamin E and B9. Depending on the health insurance the older patients purchase, the government-funded Dementia Program cover from 50% to 100% their medical bills. In 2016, approximately 130 out-patients received treatment from the program (B. Nguyen, personal communication, March 19, 2017).

### **Sample**

I consulted with the health professionals in the Dementia Program about the most culturally appropriate and effective approach to recruit caregiver participants. I applied purposive sampling (Charmaz, 2014; Guest, Bunce, & Johnson, 2006) after these consultations. The recruitment process included three steps. First, the doctor screened the list of patients who were receiving treatment in the Dementia Program. In the second step, they developed a list of primary caregivers of these patients. Third, they distributed recruitment flyers to family caregivers on the list. Family caregivers who agreed to participate in the study provided their phone numbers to the doctors or nurses in the Dementia Program. After obtaining the contacts of interested family caregivers, I made a

phone call to each of them to explain about the protocol of the study and screen for their eligibility of participation. The inclusion criteria require participants to: (1) be at least 18 or older; (2) self-identify as primary family caregivers who have provided direct, hands-on, and substantial day-to-day care (minimum 20 hours/week) for a family member clinically diagnosed with dementia; (3) have taken care of the relatives with dementia for at least one year consecutively; and (4) have no self-declared cognitive disability and can communicate in Vietnamese. In total, 20 participants who met the inclusion criteria were invited to set up an interview appointment at their preferred location.

### **Procedures**

Prior to the data collection with eligible participants, I conducted a pilot study. In the pilot study, two pilot interviews were conducted with two self-identified caregivers of older adult with memory problems. These two caregivers were selected using my personal network, and they were not included in the data analysis of the study. These interviews helped test the feasibility and appropriateness of the interview guide for a revision before data collection. In addition, reviewing the audio records of these interviews helped me learn about strengths and weaknesses of my interviewing skills.

After the pilot study, I conducted 30 face-to-face interviews, including 10 follow-up interviews, iteratively with 20 participants at their homes or the hospital depending on their references. Eight participants were interviewed for the second or third time in order to explore further their experiences. Interviews lasted from 30 to 97 minutes, with an average time of 58 minutes. Each participant received an incentive of \$15 for every completed interview.

In order to explore the experiences of participants from their perspectives, interviews were conducted inductively using semi-structured interviewing format. At the beginning of the interview, I started with broad questions, such as: *“Tell me about your experience of living with/caring for your relative.”* As the interviews progressed, I probed with more focused questions, such as: *“Why did you take your relative to the hospital for the examination? What did you think it was? What does providing care to the relative with this condition mean to you? Is there any support/challenge in your family and community that helps/hinders your caregiving for your relative? If yes, could you please tell me more about them?”* In each interview, the questions were probed flexibly depending on the responses of the participant and the flow of the interview. Demographic information of participants was collected at the end of each interview.

All interviews were digitally recorded and transcribed verbatim in Vietnamese by a professional Vietnamese transcriber. In the auditing process, participants’ identifying information was removed from the transcripts. In addition to interviewing, I conducted observations to supplement and triangulate data. As in many interviews, care recipients were with their caregivers, and I was thus able to observe their interactions and home atmosphere, as well as take field notes of my observations. Entry logs, reflective memos, and analytic memos were also conducted during the data collection and analysis process.

All interview transcripts in Vietnamese and memos were uploaded, managed, and coded with the qualitative data analysis program MaxQDA 12. Only I was able to access the coded files of participants’ data with a password. Coding the original Vietnamese transcripts helped guarantee the cultural and linguistic authenticity of the data. This

approach also helped improve the internal validity of the data (Haidar, 2013; Shibusawa & Lukens, 2004).

Adopting theoretical sampling (Charmaz, 2014; Corbin & Strauss, 2014; Creswell et al., 2007; Creswell, 2012), I conducted data collection and analysis iteratively (Charmaz, 1990, 2014). After the first ten interviews, I reviewed the interview digital records and transcripts, field notes, and reflective memos. I wrote analytic memos to identify initial codes and themes emerging from the data. The analytic memos also helped me clarify which information I needed to collect or explore deeper in the coming interviews. After 30 interviews, the theoretical sampling process ceased when I found theoretical saturation of the data, which meant no new findings emerged from the data (Charmaz, 2014; Corbin & Strauss, 2014; Creswell et al., 2007; Creswell, 2012; Guest et al., 2006; Ng & Hase, 2008; Strauss & Corbin, 1997). During the analysis process, I constantly compared transcripts with transcripts, memos with memos for theoretical sorting and theory integration (Charmaz, 1990, 2014; Ng & Hase, 2008). I also compared the emergent theories from the data with existing literature of Vietnamese family caregivers' perception of dementia, their caregiving role, and influential factors on their caregiving (Ng & Hase, 2008).

Approximately 411 pages of the interviewing transcripts were analyzed using the three-phase coding procedure (initial coding, focused coding, and theoretical coding; Charmaz, 2014). In addition, theoretical sorting, constant comparative strategies, and diagramming were applied to develop a theory responding to the research questions (Charmaz, 1990, 2014; Ng & Hase, 2008). Participants' demographic information were inputted into a Microsoft Excel Sheet.

In the three-phase coding procedure, I started with initial coding by working closely with each line of the transcripts (line-by-line coding), remaining open, comparing data, and constructing initial categories. In the next step (focused coding), I reviewed the most significant and frequent codes to examine all transcripts. This phase was followed by selecting core categories and subcategories to integrate them into a theory that addresses the research questions (theoretical coding; Charmaz, 2014). In this paper, I focused on three core categories as follows:

- (1) Vietnamese family caregivers' perceptions of dementia, including their used terms and perceived causes of dementia;
- (2) Vietnamese family caregivers' perceptions of their caregiving role for relatives with dementia;
- (3) Vietnamese family caregivers' perceptions of facilitators and barriers to their adjustment to their caregiving role for family members with dementia.

In order to improve the validity of the data, validity checking was conducted by two professors in the committee of the researcher. The two professors were native in Vietnamese and fluent in both English and Vietnamese. They randomly selected audited transcripts in which identified information was removed to examine the accuracy of translation and the logic of coding. The researcher discussed with these professors when there were disagreements in translation and coding till an agreement was reached.

## **RESULTS**

### **Participants characteristics**

A total of 20 participants participated in the study. The majority of the participants were female ( $n = 13$ ), living in urban area ( $n = 13$ ), and aged from 34 to 86

with the average age of 61. Half of the participants held a college or graduate degree. Most of the participants were retired ( $n = 13$ ), while the rest were still working as public-sector officers ( $n = 3$ ), farmers ( $n = 3$ ), or a paid house-maid ( $n = 1$ ). Besides two female participants who were either separated from their spouse or widowed, 18 participants were married and living in the same household with their spouses. The number of people in participants' households varied from two to ten people and the average number of people was four. Each participant spent averagely seven hours, ranging from three to eight hours, every day to take care of the care recipients with dementia. Participants reported they were taking care of their spouses ( $n = 13$ ), parents ( $n = 5$ ), and parents-in-law ( $n = 2$ ). Among the 20 participants, two of them were taking care of the same relative with dementia. One of them was care recipient's spouse, and the other one was care recipient's son-in-law. Both self-identified themselves as primary caregivers who carried out different caregiving duties, such as hands-on care, medication management, and decision-making related to treatment (*Table 2.1*).

The 20 family caregivers participated in the study were taking care 19 care recipients with Alzheimer's Disease, aged from 57 to 88. Among these 19 people with Alzheimer's Disease, 11 of them were male and 8 were female. Most of the care recipients had high school degrees or lower ( $n = 13$ ), whilst only six of them held a college degree. The average number of years counting from the first time the care recipients showed their dementia symptoms were five years. According to their caregivers' recall, some care recipients only showed their first dementia symptoms within a year, while some others had lived with the symptoms for approximately 20 years. Care

recipients received treatment from the Dementia Program at NGH on average of 30 months, ranging from one to 96 months.

### **Perception of dementia**

In order to inductively explore how participants perceive and label dementia in their own language, I often started the interview with a broad question, such as: “*Tell me about your experience of living with/caring for your relative.*” As the interviews progressed, I probe more focused questions, such as: “*Why did you take your relative to the hospital for the examination? What did you think it was? What do you and people in your community call these symptoms?*” In responses, participants discussed the specific terms they and others in their community used to address the symptoms of dementia before they learned about the label ‘dementia’ from health professionals at the NGH. Caregivers also provided multiple explanations to discuss the causes of dementia. Their used terms and explanations reflect their own context, including their sub-culture and religious and spiritual beliefs, as well as their educational backgrounds.

#### **A variety of terms**

Family caregivers in this study had their own terms to label dementia. Particularly, all the participants used the term ‘*being confused/confusing mind*’ (*lãn*) more than one time during their interviews to address the clinical condition of their relative. This term appeared consistently across interviews with different participants at different educational levels. This term was long used in both urban and rural areas in the north of the country for memory loss at older adults (B. N. Nguyen et al., 2018; T. B. Nguyen et al., 2018). In addition to the most used term ‘*being confused*,’ some participants perceived dementia as ‘*forgetfulness/memory loss/absent-minded*’



(*quên/giảm trí nhớ/đãng trí*), or ‘mental illness’ (*tâm thần/thần kinh*). Vietnamese people tended to associate mental illness with stigma (Meyer et al., 2015; H. Nguyen, 2015). Participants who labeled their care recipients with mental illness instead of other terms, thus, referred to their situations as “*a bad luck*.” Studies on family caregivers who were Vietnamese immigrants in the U.S. and Australia also reported the use of exactly the same terms regarding dementia (Braun et al., 1996; Liu et al., 2008; Meyer et al., 2015; Yeo et al., 2002). The consistency in the use of these terms across the contexts is likely linked to the shared culture of caregivers.

Linguistically, there is no specific term for dementia or Alzheimer’s Disease in the Vietnamese language. Besides the use of the original English terms within the health professional team, NGH psychiatrists initiated the Vietnamese terms ‘*teo não*’ and ‘*sa sút trí tuệ*,’ which were literally translated as ‘*brain shrinkage*’ and ‘*cognitive decline*,’ to communicate with patients and their families. As a consequence, participants, especially those who had limited educational backgrounds, adopted these terms in their daily lives as they commented: “*The doctor said so!*” When adopting these terms, participants tended to develop negative perceptions and emotions toward dementia, such as fear. For example, a caregiver shared that: “*I just think ‘brain shrinkage’ is a very dangerous disease. The head is the brain, and the brain is our primary organ. If it shrinks, it is really, really bad.*” (CG13, Female, 68). That said, language choice might affect caregivers’ attitudes towards the condition.

After learning about the diagnosis their loved ones, family caregivers used multiple terms interchangeably to label dementia. The most common terms, such as ‘*being confused*,’ ‘*forgetful*,’ and ‘*absent-minded*,’ were used not only before, but also

after the diagnosis of their relatives at the NGH. A few of the participants with higher educational backgrounds randomly used the original English term '*dementia*' or '*Alzheimer's Disease*' as they searched more information about the disease after talking to the health professionals. In addition, some participants used the term '*brain shrinkage*' or '*cognitive decline*' during the interviews as they explained that they heard about it from the psychiatrists and nurses at the hospital. These terms, however, were not mentioned as often as '*being confused*,' '*forgetful*,' and '*absent-minded*,' which were reported as common uses in participants' community. In other words, family caregivers were more likely to stick to what they were long familiar with from their community and social network.

### **Normal aging or something else?**

Except for a very few participants with higher educational background, a majority of the participants revealed their ambiguity and inadequate understanding of dementia. All participants asked the psychiatrists for the causes of dementia after first learning about the diagnosis. However, only a few of them actively further their own research to learn more about dementia. The rest of the caregivers revealed that their understanding of dementia and its causes remained unclear even after talking to the psychiatrist, yet they accepted the treatment for their relatives as they trusted the psychiatrists from the NGH.

Although participants lacked knowledge of dementia, they had different ways to make sense of the condition. Most commonly, participants explained dementia as a normal consequence of the aging process. '*Being confused/forgetful*' was associated with getting older. The majority of participants who were taking care of older relatives aged

70 and above considered this association a normal phenomenon in their communities. For example, a spousal caregiver shared that:

*We often say, well, he is getting older, that is why he forgets many things. Or like, he was very eloquent before, but now his speech is disruptive. People will say, “Well, he is just getting old, you know,” and getting forgetful is normal for older people. It happens to everyone, to me too – my friend said. I am three, four years younger than him and I forget things sometimes. (CG14, Female, 70)*

The association between dementia and the normal aging process is widely accepted in the Vietnamese community across contexts. Family caregivers living in Northern Vietnam shared the same use of the term ‘*being confused*,’ which they believed to be a result of the normal aging process (B. N. Nguyen et al., 2018; T. B. Nguyen et al., 2018). Vietnamese immigrants who take care of relatives with dementia also explained dementia as a part of the normal aging process (Braun et al., 1996; Hinton et al., 2008; Liu et al., 2008; Meyer et al., 2015; Xiao et al., 2015; Yeo et al., 2002). Similar to the studies on Vietnamese immigrants, participants in this study also reported divergent attitudes associated with this belief. Many participants associated dementia with ‘*normal aging*’ as they said: “*We get old, so we forget things. It is normal.*”, which is consistent with existing studies on Vietnamese immigrants (Braun et al., 1996; Hinton et al., 2008; Xiao et al., 2015; Yeo et al., 2002). On the other hand, like some other Vietnamese immigrant caregivers (Liu et al., 2008), some caregivers in this study expressed their concerns that their relatives developed dementia too early compared to others people at the same age in their community, and they referred it to a sign of ‘*poorly aging*’ due to bad nutrition or something else. A male caregiver assumed that his father developed dementia because he ate too little with only tofu and vegetables.

In addition to the attribution to normal aging, most participants adopted the assumption of physical conditions as a possible cause of dementia to explain their relatives' conditions. Participants mentioned a wide range of physical conditions that they believed to be contributors to dementia. The leading possible physical causes were noted as brain damage from post-war or post car accident injuries, insomnia, poor nutrition, and giving birth too many times. The explanations of brain damage and other physical injuries were common across cases of care recipients who had lived through the Vietnam War. These results are mostly consistent with what were found in Vietnamese immigrants when they discussed their perceptions of the causes of their relatives' dementia. The leading causes of dementia according to Vietnamese immigrants included brain diseases, blood diseases or stroke, overeating, medication abuse, and the imbalance between yin and yang (hot and cold) in the body (Yeo et al., 2002).

Psychological traumas or distress (e.g., loss, grief, depression, and post-traumatic stress disorder (PTSD)), overthinking or under-thinking, and hazardous working environment, were also shared by participants when discussing possible causes of dementia among care recipients. Particularly, many caregivers did not differentiate dementia from grief, depression, and PTSD. Instead, they tended to clump all forms of care recipients' psychological distress together and labeled them depression. A daughter-caregiver connected her mother's dementia with the deaths of her sister and nephew: "*I think it (dementia) was caused by the sudden deaths of my sister and nephew in Germany. My mother was shocked and has been so sad since two, three years ago. She has been so different when she was alone at home.*" Another spousal caregiver believed that her husband developed dementia because he '*stressed out*' for not having a grandson to

inherit his last name and ancestor veneration: “*He just needs a grandson. He keeps thinking about that and gets stressed out. He is very patriarchal. If he had a grandson now, he would recover (from dementia) without any medicine!*” (CG12, Female, 68) (in Vietnamese tradition, only male descendants are granted the right to carry on the ancestor veneration, a key spiritual practice of Vietnamese families). Vietnamese immigrants residing in the United States also considered past trauma, grief, and loss from the war in Vietnam as the possible causes of their relatives’ dementia (Meyer et al., 2015). Overall, even though Vietnamese family caregivers in this study did not have clear and adequate understanding of dementia, particularly from the biomedical perspectives, they developed their own explanations to make sense of the condition. These perceptions reflect their sociocultural context of dementia and caregiving.

The results suggest that Vietnamese family caregivers adopted multiple approaches to make sense of dementia. Hinton, Franz, Yeo, and Levkoff (2005) presented the most common explanatory models of dementia including biomedical, folk, and mixed models. Biomedical model refers to the pathological approach which emphasizes the nature of dementia as abnormal brain-based disorders (Hinton et al., 2005). Folk model refers to terms and explanation that fall outside the biomedical model, such as dementia as normal aging. Mixed model is a model which combines both biomedical and folk elements to explain the nature and causes of dementia (Hinton et al., 2005). What were found in Vietnamese family caregivers in this study show that they adopted a mixed model combining both biomedical and folk approaches to make sense of dementia. As all caregivers were recruited from the NGH, they all referred to dementia as a brain-related disorder that needed medical treatment. On the other hand, they still associated dementia

with normal/poorly aging, or physical injuries, or psychological distress. Their folk and biomedical approaches coexisted without excluding each other. This result was consistent with the study results on multi-ethnic family caregivers of Hinton et al. (2005).

### **Morally based perception of caregiving for relatives with dementia**

All Vietnamese family caregivers participating in this study discussed caregiving for a relative with dementia as morally based, reflecting their cultural values rooted in the Confucianism tradition. All participants shared a perception that caregiving was primarily a family duty, which is supported by studies on Vietnamese immigrants (Braun et al., 1996; Hinton et al., 2008). Most of the participants in this study had lived with or nearby and provided some sorts of care for the older care recipients before the onset of symptoms. After learning about their relatives' diagnosis of dementia, participants automatically took on the role of primary caregiver. Most participants assumed that they would be the best person-in-charge of caregiving because they had time and/or experiences in caregiving in general. Although all participants associated their caregiving roles as a way to fulfill their moral and traditional values, there were differences across children and spousal caregivers. Adult children caregivers highly valued filial piety or, a strong sense of responsibility and obligation, which led them to willingly accept the caregiver role. On the other hand, spousal caregivers consistently emphasized affection and gratitude (*tình nghĩa*) as the key motivators in their carrying on their caregiving role.

### **Filial piety or a strong sense of responsibility and obligation among adult child caregivers**

Adult child caregivers in this study highly emphasized the traditional value of 'filial piety' (*đạo hiếu*). They mostly referred filial piety to 'responsibility/obligation'

(*trách nhiệm/nghĩa vụ*) for respecting and taking care of their parents. Confucianism's concept of filial piety shapes the values of love, compassion, and sacrifice between children and parents (Braun et al., 1996; Hinton et al., 2008; Truong, 2015). As Confucianism places a strong importance on '*family*' as compared to '*individual life*,' collectivism and familism surpass individualism. Vietnamese parents tend to sacrifice their lives to their children. In turn, children are expected to pay back by respecting and taking care of their parents when the parents get older to fulfill the reciprocal '*parent-child contract*' (Braun et al., 1996; Hinton et al., 2008; Truong, 2015).

Despite holding the key value of filial piety, adult child caregivers varied in their attitudes toward the commonly accepted values of responsibility/obligation.

Responsibility/obligation might contain either positive or negative meaning to participants. To most participants, being able to take the responsibility of caregiving for their older parent was a privilege, as a daughter shared:

*Of course, my caregiving is very meaningful to me. My siblings and I all felt it was our responsibility, we all had the same feelings about it. First of all, taking care of a father is primarily children's responsibility. Second of all, I find that our caregiving really works out, and we all feel relieved with the result (of the father's health). (CG15, Female, 51)*

However, not all participants associated their caregiving responsibility with positive feelings. To some participants, caregiving responsibility was assigned to them based on their social roles, such as a daughter-in-law. This assignment forced them to carry out the caregiving duty to fulfill moral standards and social expectations associated with their social roles even when they were too burdensome to maintain. A widowed daughter-in-law described her caregiving responsibility for her mother-in-law at an advanced stage of dementia as '*tired*' and '*desperate*,' yet she could not quit: "*It is the*

*matter of doing your filial duty to your parents. It is about our morality. It is not a business that you can quit when you are tired of it.” (CG16, Female, 59)* This caregiver and others associated filial piety with ‘conscience’ (*hương tâm*), ‘morality’ (*đạo đức*), and ‘role modelling’ (*làm gương*) for other people in the family, despite the negative consequences for themselves. Similar results were found in studies on Vietnamese immigrants who believed that their sacrifice and devotion to the care duty for older parents would lead to blessing for the family, as well as teach the youth in the family through their example (Braun et al., 1996; Hinton et al., 2008; Truong, 2015). As a result, quitting the role of a primary caregiver was not a choice to participants in this study in spite of the hardship it brought to their personal lives.

### **Affection and gratitude among spousal caregivers**

Profoundly rooted in the Vietnamese traditional culture, all the spousal caregivers in the study rationalized their caregiving role using the key values of ‘*tình nghĩa*’ (*affection/love and gratitude*). ‘*Tình nghĩa*,’ a combination of two different words, ‘*tình*’ (*affection/love*) and ‘*nghĩa*’ (*gratitude*), was considered the two moral pillars upholding Vietnamese families. ‘*Tình*’ (*affection/love*) referred to the mutual love and affection developed between husband and wife. This word reflected the emotional aspect of a relationship. ‘*Nghĩa*’ (*gratitude*), on the other hand, reflected the conscience aspect of a person to another in a family relationship. ‘*Nghĩa*’ often referred to the gratitude of a man/woman to his/her spouse for devoting to their marriage and family nurture. ‘*Nghĩa*’ (*gratitude*) also transferred a meaning of ‘*paying it back*’ for the love and support a person received from others in the family. A participant shared:

*I think it (caregiving) is all about love and gratitude. Since we have lived together, he has been too good to me. We have shared our lives together for*



*years, and then unfortunately he got this disease (Alzheimer's Disease). He was not a selfish or irresponsible man to the family at all. He devoted his life to me, his children, and grandchildren. I think no one wants to have this disease, and no one can ever predict it. It is just a bad luck. So I have to take care of him... I must treat him fairly. I must treat him well to have my mind in peace. I cannot quit (caregiving). (CG14, Female, 70).*

While ‘*tình nghĩa*’ (*affection and gratitude*) were considered the two moral foundations upholding Vietnamese families, each component was weighted differently. To most participants, gratitude, rather than affection, was the fundamental value motivating them to endure the hardship of their caregiving duty. Caregivers taking care of their spouses at the advanced stage of dementia had to deal with the frustration of not only caregiving demands, but also their relationship changes. Many of them were struggling with their spouses’ cognitive impairment, irritating behaviors, and dependence in activities of daily living (ADLs). Participants gradually lost the sense of intimacy with their spouses affected by Alzheimer’s Disease. Only gratitude kept them going with their caregiving duty, as a participant noted: “*Only because of gratitude, (I keep taking care of him). I have no intimate feelings for him anymore.*” (CG05, Female, 71).

Despite the loss of intimate feelings towards the care recipients, all spousal caregivers firmly believed that they were the best person-in-charge of caregiving for their spouses. Not only their strong attachment to their spouses, but also their lack of trust in transferring the role to their children motivated them to keep carrying on the primary caregiving role. The spousal caregivers in this study expressed their concern about the future if they might pass away before the care recipients or the care recipients might progress to a too challenging stage of dementia that they might not be able to handle with their own old age and deteriorating health conditions. Without criticizing their adult children, spousal caregivers in this study related to the fact that their adult children were

all responsible for their full-time job and their own families with their own children. Thus, the participants were worried that their adult children would not be able to devote to caregiving for the care recipients as they were doing. For this reason, most of the spousal caregivers in the study were open to the option of a nursing home in the future if this option was available and affordable, which is different from the results of existing studies with Vietnamese people (Truong, 2015) and Vietnamese immigrants (Meyer et al., 2015). This way of thinking reveals that spousal caregivers stood for the best of the care recipients rather than their fear of losing social reputation, which is distinguished from previous studies (Meyer et al., 2015; Truong, 2015).

### **Perception of facilitators and barriers to the adjustment to caregiving role**

In this study, family caregivers were asked to describe what they perceived as the facilitators and barriers to their caregiving on the daily basis. Participants listed multiple factors at both personal and structural levels which either facilitated or inhibited them in their care activities. Consistently across caregivers' discourses, care recipients' manageable health condition, their own stable health condition, personal beliefs and commitments to caregiving, and social support importantly facilitated their ability to continue the caregiving role. In contrast, caregivers perceived patients' behaviors and psychological symptoms of dementia, caregiving burdens (e.g., time constraints and social isolation), lack of social support, and social pressure to provide care and judgment from others as key barriers to their caregiving role.

#### **Facilitators**

*Personal level factors.* Caregivers in this study emphasized the importance of care recipient's manageable health condition, their own stable health status, as well as

their strong beliefs and commitments to their caregiving role in motivating them to carry on the role.

*Care recipient's manageable health condition.* Care recipient's health condition including the level of cognitive impairment, disruptive behaviors, and dependence in ADLs played a key role in facilitating or inhibiting participants' caregiving. Participants caring for relative with mild cognitive impairment who were still able to maintain their independence in ADLs with minimum disruptive behaviors considered their care recipients' condition an advantage. In the cases of those participants, they did not have to devote too much time in supporting their care recipients' ADLs, such as feeding and bathing. Participants also felt relieved and easy with their caregiving when care recipients did not demonstrate problematic behaviors, such as wandering. As a spousal caregiver shared: "*Everything is just like usual. Other people (with dementia) need to be cared for completely. She (the care recipient) still can walk around, curse others, use the bathroom, and bathe herself.*" (CG17, Male, 75). The manageable health condition of care recipients allowed primary caregivers and other family members to maintain most of their daily routines with little changes in their schedule. Caregivers in these cases also reported minor health problems and little distress.

*Caregiver's stable health condition, personal beliefs, and commitment.* Data analysis revealed some key factors which caregivers considered them protective factors for their adjustment to their caregiving role. These factors included their stable physical health condition, strong personal beliefs and commitment to their caregiving role. First, according to participants, good and stable health status was very important for them to carry out demanding caregiving activities for a long time. Taking care of a relative with

Alzheimer's Disease was challenging and care recipients' conditions were often unpredictable. Many care recipients lived with comorbidity of Alzheimer's Disease and one or more other diseases, such as high blood pressure and Parkinson. These care recipients needed health examination and hospitalization quite often which required their family caregivers to devote tremendous time and energy in caregiving. A spousal caregiver commented on the time she took care of her husband in the hospital: "*I have good health and rarely get sick. If I did not (have good health), in the past ten days, I would have collapsed.*" (CG08.2, Female, 60). Like this caregiver, many participants expressed their appreciation for having good health to endure the hard work of caregiving.

In addition to the stable health status, participants' beliefs of and commitments to their caregiving roles facilitated how they took in the role and carried it out. As mentioned above, family caregivers in this study consistently upheld strong values of filial piety (among adult child caregivers), affection and gratitude (among spousal caregivers), which were deeply rooted in their culture and social norms. The traditional Vietnamese culture and social norms are dominantly influenced by Confucianism and Buddhism (Braun et al., 1996; Hinton et al., 2008; Liu et al., 2008; Meyer et al., 2015; M. D. Nguyen, 1985; Yeo et al., 2002). Especially, more than a religion, Buddhism with its teaching about karma (cause and effect of an action), compassion, and good deed practice, have shaped social norms of Vietnamese families regardless of their announced religions. Taken together, family caregivers had their complex culture-based belief system of caregiving which helped them: (i) make sense of the illness and situation; (ii) accept the role and its challenges; and (iii) search for the meaning of and make peace

with their caregiving. For example, a spousal caregiver explained her situations from the view of karma, which then helped her accept her husband's condition with ease:

*Sometimes, I wonder why a perfect man like my husband becomes this. According to the Buddha, it is karma. Buddhist monks taught me that. It may not be from this life, but from a different life long time ago in the past. We have to pay for our karma from the past lives. Now I try to do good deeds to earn good karma for my children and grandchildren... It is how it works, so I accept it. I believe in Buddhism.” (CG14, Female, 70).*

Having positive beliefs of caregiving helped participants adjust easily to their role. Some participants expressed their joy and appreciation of having a chance to take care of their loved ones. They found their caregiving meaningful and fulfilling. This attitude also motivated them to commit to their caregiving without feeling burdensome or distressed. A daughter-caregiver revealed about the meaning of caregiving to her:

*It is really meaningful to me. I remember what my father had done for me. What I have done for him now is nothing compared to that. It is the love between father and his children. I do not know about other families, but in mine, my father had taken care of me and my siblings from the tiniest things since we were small... My three other sisters and I were so lucky to have a family like that where we received a lot of love. Even when I was pregnant and gave birth, my father still took care of me. That is why I think if my father did not mind he was a man and still took care of me at those times, why cannot I take care of him? (CG10, Female, 44).*

This caregiver, like other adult child caregivers in the study, found the meaning of caregiving by connecting it to her culture-based belief system of filial piety and karma. Taking care of her father with dementia was a method for her to show gratitude and pay back the love and care she received as a child. Fulfilling this reciprocal “parent-child contract” (Braun et al., 1996; Hinton et al., 2008; Truong, 2015), the participant found peace and satisfaction, including the sense of pride, as she met her moral standards and the social expectations associated with her role as a daughter. In other words, the culture-

based belief system and role fulfilling established the unique caregiving mechanism among Vietnamese family caregivers in dementia care.

***Interpersonal and structural level factors.*** Besides personal factors from care recipients and caregivers themselves, the data analysis showed that social support played a key role in facilitating participants' ability to provide care. During the caregiving process, participants received different forms of social support, including formal support and informal support. The most common formal support the care recipients and their caregivers received was the financial support for medical treatment in the Dementia Program. Through the Dementia Program at NGH, the government provided each patient clinically diagnosed with dementia and using health insurance a financial aid to cover from 50% to 100% of their medical bill related to dementia treatment only. Patients purchased prescribed medication for dementia symptoms, such as Aricept and Razadyne (Galantamine) on a monthly basis. The financial aid significantly reduced their financial burdens. A participant commented: *"Since she was transferred to this program, our expenses reduced a lot. We do not have to pay for extra fees, her insurance covers it."* (CG17, Male, 75).

In addition to the financial aid, healthcare professionals, especially psychiatrists in the program, often provided family caregivers with informational and emotional supports. Most participants, particularly those whose relatives had been in the program for years, endorsed the support they had received from the psychiatrists.

*I have to say that the doctor is very caring to her patients. She explained everything thoroughly and carefully. She gave me detailed instruction. For example, to patients like him, we should not speak a long sentence, just speak every word slowly. Like "Do you want to have some water?" we should speak every word slowly along with handing him a cup of water to help him remember it. Something like that. She also guided me how to take care of him and observe*

*the changes in his condition. For example, before he was not shaking at all. But now he starts shaking like he gets a bad cold. (CG14, Female, 70)*

Participants also perceived informal support, particularly the support from their family, as a pivotal protective factor to their caregiving. Participants referred to not only their nuclear family, but also to their extended family. In many cases, the participation and support of the extended family were important, and they significantly affected the results of the caregiving process. Family provided care recipients and caregiver participants with tangible (such as money and supplements), informational, and emotional supports. Some participants had multiple siblings or different relatives living nearby. In most cases, they divided their caregiving duties, such as taking shifts to supervise the care recipient or joining each other to take care of the care recipient at the same time. For example, a participant shared that all of his siblings joined him to escort and comfort their father to the hospital every month. As primary caregivers, most participants revealed that they tended to adjust to the caregiving role easily when their family members showed them empathy, encouragement, some hands-on help, and some sources of financial support.

*My daughter-in-law is such a good person. Even though when she first got married to my son, she did not have a lot of money, she always gave me money to buy medication for my husband if she found out that he needed treatment. Sometimes, she gave me some money, like 500,000 or one million Vietnam Dong (approximately US\$25 or \$50) and told me: "Mother, you can use them for medication or food." She is such a nice daughter-in-law and I have nothing to blame her. I have two daughters-in-law, and they are both very good, so do my sons. I do not have to say anything, but they just take a good care of their father. They save money to buy his medication without any hesitation. (CG01, Female, 56).*

In addition to family support, some participants commented on the extra supports they received from a hired house-maid. Taking care of a care recipient at the advanced

stage required significant time to supervise and aid the care recipient with ADLs whilst doing other chores. Some participants with the financial resources decided to hire a house-maid to help them with their caregiving. Their house-maids either visited and helped them within a few hours every day or stayed in their houses for 24/7 services with only a few days off every year. These house-maids were non-professional, self-trained, and they mostly helped with the chores inside the house. They also provided hands-on care if participants required them. Considering that a 24/7 in-home maid was paid approximately four to six million Vietnam Dong (\$200 – \$300) per month, plus shared home-meals and accommodation inside the house, a few participants could afford this service with or without their families' financial support. Even though participants were still in-charge of all the hands-on care, having a house-maid released them from some chores and provide short-term respite at least for a short break outside of the house. To some participants in the rural area, they also received support from their neighbors, such as a warning about the wandering care recipient.

In short, social support played a critical role in the adjustment process of a caregiver to his/her caregiving. Being consistent with the results found among Vietnamese immigrants (Meyer et al., 2015), Vietnamese family caregivers in this study highly favored support from family and friends. Primary caregivers tend to request and receive hands-on care support from other members within their extended families, such as siblings (Meyer et al., 2015). The amount of social support, particularly informal support from family, a caregiver received reflected the cohesion in his/her family. This support contributed to shape the attitude of caregivers toward their role, as well as the results of caregiving activities.



## **Barriers**

*Personal level factors.* As primary caregivers, participants confronted multiple challenges that inhibited them from successfully adjusting to their new role in the context of dementia care. The data analysis revealed different barriers at the personal level, including care recipients' challenging conditions, as well as caregiving burdens associated with their role demands and conflicts.

*Care recipients' challenging conditions.* The critical condition of the care recipients was reported as one of the worst difficulties that participants had to deal with during their caregiving. Caregivers often struggled with their caregiving role when the care recipients were at a more advanced stage of Alzheimer's Disease with moderate or severe cognitive impairment, frequent disruptive behaviors, and high dependence in ADLs on caregivers. In the study, 19 care recipients were at different stages of Alzheimer's Disease. Some of them were at the beginning stage of the disease, and they were able to maintain their daily life with minor support from their family caregivers. Two third of the participants in the study self-rated their care recipients' conditions more critical and concerning. As the average number of years of dementia exposure was five years and the longest duration 20 years, care recipients progressively moved from early dementia with mild to moderate symptoms, to late dementia with severe symptoms. Participants referred to the most stressful and difficult periods when patients were dependent, experiencing moderate to severe cognitive impairment, and disruptive and even violent behaviors. A spousal caregiver told about her daily care activities for her husband who progressed to an advance stage of dementia:

*Because he does not know anything anymore, does not understand anything, including hygiene. When I put my fingers into his mouth to clean his teeth, he bit*

*me. In the beginning (of the disease), I was still able to make him wash his mouth and brush his teeth. But then, he could not do that anymore. His mouth was just full of toothpaste. He did not remember to spill it out or use water to rinse it off. It keeps being like that. Then I have to take care of the rest (of cleaning his teeth). Keep being like that. I have to clean him. Hitting, biting my hands, something like that. Sometimes it is so frustrating. Or when he needed to use the bathroom, he did not let me clean and change his clothes. We wrestled with each other. So frustrating. (CG14, Female, 70)*

Some other caregivers who took care of relatives with severe symptoms of dementia shared the same frustration. As Alzheimer's Disease progressed by time, most care recipients' conditions needed more and more attention, time, and effort in caregiving. A few caregivers reported that their care recipients progressed to the stage of unmanageable and inappropriate toileting which worried and frustrated the caregivers considerably. Some of these care recipients also showed aggressive behaviors, and sometimes violently attacked caregivers when the caregivers tried to help them wear diapers or clean up after toileting. In several home visits and interviews, the caregivers explicitly discussed the unpleasant waste smell in their houses resulting from the care recipients' problematic toileting behaviors. They also reported a significant amount of time spent every day to supervise and clean up after the care recipients as a caregiver revealed:

*The upper floor in my house smells awfully like ammonia. No matter how many times I clean that floor, the smell is still there. He pees everywhere, on the walls, in the corners... I am so nervous whenever we travel somewhere. I cannot sleep, just follow him everywhere. Like last time, we stayed in a five-star hotel with very nice carpets and curtains. Just one minute of my distraction, he peed in the corner (of the hotel room). (CG05, Female, 71).*

In these cases, caregivers gave up their usual routines and spent more time on hands-on care for the care recipients. The longer the care recipients lived with

Alzheimer's Disease, the more time and hands-on care the caregiver had to devote to caregiving duty.

*Caregiving burdens associated with role demands and conflicts.* Care recipients' severe symptoms were associated with caregiving burdens, as well as role demands and conflicts towards caregivers. Across interviews, the family caregivers described a variety of caregiving hardships, such as time constraints and social isolation, and their corresponding reactions, such as exhausted and depressed, to address the burdensome natures of caregiving without explicitly using the word 'burden.' This is explained by the traditional culture and social norms which expect family members to care for older relatives as a form of filial obligation and good deed practice (Braun et al., 1996; Hinton et al., 2008; Truong, 2015). In other words, family caregivers in the study acknowledged multiple caregiving burdens, yet named them differently to avoid social judgment stemming from their role expectations. Caregiving burdens became more critical when care recipients' condition progressed and required more time and efforts of participants in hands-on care and supervision.

Intensive workload, time constraint, social isolation, and financial burden were found consistently across participants' interviews. These results are similar to caregiving burdens reported by family caregivers living in the North of Vietnam (B. N. Nguyen et al., 2013; Truong, 2015) and Vietnamese immigrants (Braun et al., 1996; Hinton et al., 2008; Liu et al., 2008; Meyer et al., 2015; Yeo et al., 2002). Even though all participants received some sources of financial support from care recipients' health insurance and other family members, many of them still faced financial burdens to secure the treatment for their loved ones. Health insurance covered from 25% to 100% of the fundamental

medication for Alzheimer's Disease. Besides, participants paid for other supplements, additional tests, and transportation fee to visit the hospital once every month out of their pocket. As a caregiver commented: "*Health insurance helps with medication fee. But it does not help that much.*" It is worth mentioning that most participants had been taking care of their relatives with Alzheimer's Disease for over four years. Two third of the participants were older adults taking care of their spouses with Alzheimer's Disease. While retired participants could be able to use their retirement pension to cover their spouses' healthcare fee, some others were farmers living in the rural area without any secured pension. Instead, they had to find part-time jobs or try to find time to work on the farm to make additional income. A participant once commented, Alzheimer's Disease is "*a disease of rich people.*"

Caregiving placed pressure on not only participants' budget, but also on their time, career, and social relationships. Many long-term caregivers shared the same situation of "*no more friend, no more going out*" and "*stuck within the four walls*" with the care recipients. All of these hardships were inter-correlated and integrated with each other and caused participants' physical and psychological health problems. Time constraint and social isolation burdened participants and mentally and psychologically inhibited their adjustment to their caregiving role. Participants who had to take care of care recipients at a severe stage of Alzheimer's Disease lived with caregiving burdens daily. Without or with only limited social support, these participants tended to feel trapped and stuck with their caregiving role, and eventually they gave up some other priorities, such as their own career and social relationships. A daughter-caregiver shared her story:

*It (caregiving) is really tough. Very stressful. People do not often think about caregivers. I am lucky because my siblings and I get along, and we understand each other. We help each other to take care of our father. It reduces the workload and lessens the stress. If I were alone (in caregiving), I would not have known what to do. I guess it would have been very exhausting and I would not have been able to take it because I was teaching back then. Teaching was different from other jobs. I could not ask for a day off because if I took a day off, it would have affected all my students. At that time, I went to teach, took care of my family business, and took care of my father. When I was in the hospital with my father, I still worked from there on the phone to keep the business running. It was so busy and exhausting. My health was considerably affected. I have just requested to retire at the beginning of September. I applied for early retirement. (CG15, Female, 51).*

Caregiving burdens were also associated with role demands and conflicts towards caregivers. Caregiver was only one among different roles each participant carried. Most of them confronted multiple challenges to maintaining different roles at the same time, as well as meet different social expectations associated with their roles. Role demands and conflicts, hence, were noted as a barrier to the adjustment to caregiving role of most participants, particularly women. To meet the demand of the caregiver role only was a challenge to most participants who were long-term caregivers of a care recipient with severe Alzheimer's Disease. To carry out their caregiver role, they actually played different roles to meet care recipient's needs only. In other words, results from this study show that caregiver role was roles-nested-in-role. A spousal caregiver self-identified her as “a doctor, a wife, a house-maid” for her husband with Alzheimer's Disease.

In addition to the caregiver role, which was already a roles-nested-in-role, participants had to fulfill different roles and social expectations, such as a wife, a full-time employee, a daughter, a mother. Social expectations were likely more complex and put more pressure on women. Debating among different roles to play along at the same

time, most participants found themselves stuck in between role conflicts and distress. As a participant shared:

*My husband was too sick, I kept working. My father was sick too, but I could not even visit him. My siblings blamed me for only caring about my in-law family and not caring about our parents. Getting married to a sick husband is tough, too much work needs to get done, I have to take care of them all. When I take care of my husband, I cannot take care of my parents. (CG01, Female, 56)*

Furthermore, it was quite common among female participants that many of them were taking care of multiple people in the family at the same time, including the care recipients with Alzheimer's Disease, their children, and grandchildren besides other roles of a wife and an employee. When there was someone in the family hospitalized for a medical issue, female participants were always involved. Particularly, a forty-four-year-old, female participant with public health background was working full-time from 9 am to 5 pm as a public-sector officer, running her private clinic after work, and taking care of two relatives with dementia (her father and father-in-law) and a grandmother with chronic diseases besides her roles as a wife and a mother. With her public health degree and experiences in the field of healthcare, she voluntarily took the responsibility of planning and decision-making for medical issues for all these three relatives. She lived in the same household with her father and commuted to different provinces to check on her father-in-law and grandmother every week. This participant slept approximately four - five hours every day. The rest of the day, she devoted to different roles. She confronted not only intensive workload and tight schedule, but also critical role demands and conflicts in order to “*avoid any complaint.*” The power hierarchy in the family made it more difficult for her, a middle-age daughter-in-law, to fulfill her caregiving roles. Other older caregivers, such as her aunts, sometimes did not totally approve or feel comfortable

with her recommendations. She sometimes found herself in a controversial situation, in which she tried to make the best medical decisions for the care recipients, but avoided making other caregivers feel belittled and disrespected.

Role demands and conflicts towards female caregivers in dementia care reflect the social norms, especially gender norms in Vietnam. Confucianism significantly shapes Vietnamese people's perception of gender role in caregiving. Existing studies show that males and females assume that caring for older parents, especially those with dementia was primarily women's role (Braun et al., 1996; Hinton et al., 2008; Truong, 2015). Male and female caregivers refer to social discourses that in the traditional society, men are expected to take care of 'big' issues outside the family, while women are responsible for all domestic issues. In caregiving, men often play the role of decision-makers, while women provide the direct care to the ones in need. Moreover, in case of older parents with dementia, daughters or particularly daughters-in-law are often in charge of care delivery as well as spend as much time with the sick parents as possible (Braun et al., 1996; Truong, 2015).

***Interpersonal and structural level factors.*** Caregiving for an older relative with Alzheimer's Disease was a challenging duty and participants revealed different barriers at the structural level, including lack of social support and social pressure and judgment associated with their role expectations. These barriers rooted in the context of participants and reflected the common beliefs and cultural symbols of multiple roles played by participants in their family and community.

***Lack of social support.*** Social support played a pivotal role in supporting the adjustment process of participants to their caregiving role, as well as impacted the

caregiving outcome and participants' well-being. However, not all participants perceived that they received sufficient social support, including both formal and informal supports. As participants had different backgrounds, located in different locations, and lived with different families in distinguishable atmospheres, the social supports they received also varied across cases. First, many participants reported the lack of formal support which inhibited their caregiving. More than a half of the participants did not live in Hanoi where the NGH was located, with one third of participants living in rural areas. Caregivers and their care recipients traveled from other towns or even provinces far way from the hospital at least once every month to receive the monthly checkup and medication for the care recipients. This monthly traveling became a hardship to many participants as it cost them a lot of time, money, and physical effort, as a participant shared:

*We traveled (from the hospital) in the morning and got home in the afternoon. At 9 am, we took the bus which traveled on highway to L.C. city (a remote mountainous area in the north of Vietnam). After getting to L.C. city, we needed to travel extra 100 kilometers to get home. But that route even took longer than the route from Hanoi to L.C. city because of the difficult roads in the mountain with a lot of bends and slopes. It often took three hours to complete that road. It took the same time to travel from Hanoi to L.C. city. Traveling on a highway was not too bad, but on the way to get home in the mountain, my husband had motion sickness easily. Last time, we traveled home, I did not give him a pill, so he got motion sickness. It would have been nice if the hospital allowed us to have his checkup and medication refill every three months because we live so far away. Traveling is expensive too. Our bus tickets cost 500 – 600 thousand Vietnam Dong (US\$25-30) for one-way. Round trip would cost 1.2 million Vietnam Dong (US\$60). We are still lucky because our children lived in Hanoi, so we only have to pay for the bus tickets. If our children do not live here, I would have to pay for accommodation. It would be very, very expensive. (CG13, Female, 68).*

Despite the monthly hardship this participant and her husband went through, they did not have other choices. As many other participants, they lived in underserved areas where there was not enough formal support for dementia examination and treatment in



their location. The NGH was the one of the few national-level hospitals providing specialized geriatric care, including for dementia.

In addition to the lack of formal support available in the residential areas, participants struggled with their caregiving duty with or without limited help from other family members. Different from some participants who received significant supports from their adult children, siblings, and other relatives, many other participants did not have this source of support due to their family structure and dynamic. A half of participants lived with their spouses only in their households and their children mostly lived far away in other cities, or even countries. They still received some tangible supports, such as money, from their children. The absence of adult children at home, however, was perceived as a great barrier to these older participants. A spousal caregiver expressed her concern about having no children home:

*I have two daughters (who got married and lived far away). Now just two of us take care of each other. If I get sick, I will not be able to do anything even if I am worried. I just believe in the doctors and put my hope on them. If I am worried too much and get sick, no one will take care of him. Just two of us live together now, our daughters both got married. I have no one to lean on. (CG11, Female, 56)*

Many other older participants were in the same situation. They still received some tangible supports, mostly money, from their adult children. Most of the participants accepted the situation as they explained that their children needed to work in a tight schedule and financial support was the most practical mean they could provide. Hiring an hourly or full-time in-home maid was considered a solution to the lack of family support in hands-on care. This solution was expensive, unstable, and unaffordable to many participants. In the study, only four participants, who cared for a care recipient with advanced Alzheimer's Disease and had stable financial support, hired a maid to help with

their caregiving duty and household chores. The maids mostly helped with basic daily chores, such as cooking and cleaning, and sometimes assisted the caregivers with supervision of the care recipients when the caregivers needed to go out for a few hours. Despite having a maid, the caregivers were still in charge of most hands-on, direct care activities. This care practice among caregivers with a hired maid could be explained with the two reasons. First, letting the maid to completely care for the care recipients was against the traditional values of family cohesion and responsibility, which might lead to social blaming from the community. Second, the primary caregivers did not place their trust on the maids. From their perspectives, the non-professional, untrained maids who worked simply for income would not care for the care recipients with much “*patience and understanding*” as a family member would do. A male spousal caregiver shared that, although he seriously needed a maid, he once rejected a young maid because he did not believe that a maid at a young age could be able to understand, empathize, and provide care with great patience for his wife. Besides, even when a caregiver could afford a maid, he/she still struggled to maintain the service due to the high demand of maid in general and the unstable labor market. Hired maids were in a great demand among urban families of full-time job parents with small children and stable income, and they were well-known for job-hopping across households. The participants who hired a maid all complained about the hassle of constant recruitment for a new maid every few months.

Besides, even with the support of a hired maid, the lack of responsibility sharing and emotional support from family was the greatest barrier to some participants. In some particular cases, participants were financially independent and stable. As taking care of a care recipient with advanced Alzheimer’s Disease restrained their time, modified their

lifestyle, and drained them physically, mentally, and emotionally, they expected some minor understanding and help with hands-on care from other family members. When this expectation was not met, these participants burned out and caregiving became more challenging to them. In a typical case, a widowed participant was taking care of her mother-in-law with advanced Alzheimer's Disease with a hired maid, but she did not receive any support from her three sisters-in-law. Caregiving for her mother-in-law, indeed, caused family conflicts among the siblings. The participant emphasized that she did not need any financial support from her three sisters-in-law, but only wanted decent help with hands-on caregiving and time-sharing, as she was 'trapped' and 'miserable' with the care recipient for years:

*I only hope that my sisters-in-law would have been more responsible and taken care of her for only a few days. But they are too ignorant and selfish. They do not care about their own mother, they merely ask about her. Sometimes, I feel so bad for her because she is so miserable. But taking care of her is exhausting. Really exhausting. I am only her daughter-in-law but I have to take care of her all the time. I wish my sisters-in-law were more responsible, care more about her, and help me with caregiving, I would have been less miserable. Living like this is just too desperate, too desperate [crying]... I do not know (I have to do it) until when. Keep being like this, I may even die before her." [crying] (CG16, Female, 59)*

The need of family support, particularly emotional support, is critical among Vietnamese family caregivers whose culture emphasizes familism and the sense of pride regarding family cohesion and harmony (Braun et al., 1996; Hinton et al., 2008; Truong, 2015). No or very limited family support, especially in the situation of inadequate formal support in dementia care in Vietnam (B. N. Nguyen et al., 2018), might break the belief system of the family caregivers, a belief deeply rooted in their culture. The lack of social support also likely results in negative coping outcomes among caregivers, such as

maladaptive and burnout due to long-term care without respite (Braun et al., 1996; Hinton et al., 2008; Liu et al., 2008; Meyer et al., 2015; Truong, 2015; Yeo et al., 2002).

*Social pressure and judgment.* At the structural level, social pressure and judgment became barriers for participants to adjust to their caregiving role. Participants, especially women, played different roles in the family and community, such as a daughter, daughter-in-law, wife, mother, and employee. Their families and communities held specific expectations associated with their roles. Sometimes, the expectations were too high and impractical in the situation of caregiving for a relative with severe Alzheimer's Disease. Expectation and pressure firstly came from the family. For some participants, before becoming Alzheimer's Disease caregivers, they were able to satisfy all family role expectations exceedingly well. Other family members often kept upholding high expectation for caregivers, even in caregiving. High expectations, unrealistic standards, and sometimes negative judgments from family members can become critical pressures, leading to caregivers to feel lonely, isolated, misunderstood, and burnout.

A participant shared her story about the barriers she faced from high expectation and pressures which her adult children placed on her. She used to be the breadwinner of the family and take care of everyone, including her husband and children. She worked diligently to buy her own house and two other houses for her sons. She helped them to find their jobs and supported them in their careers. When she retired and her husband showed the symptoms of dementia, she only focused on taking care of him. For over 11 years living with dementia, her husband's condition progressed, and his behaviors

became more problematic. She felt heavy burdens stemming from daily caregiving and wanted some help. Her children blamed her for not being patient enough to her husband.

*They told me: "Well, sometimes you just were not patient to him." I was so angry and told them: "He is your father. From tomorrow, I will not take care of him. You will take turn to take care of him. I just need you to take care of him in a week, or three days, or even only one day. I will see if you can stand it." When I told them that, they kept silent... When they said that to me, I cried and told them: "You all say it well. Why don't you try taking care of him?" (CG05, Female, 71)*

Some participants experienced different levels of social pressure and judgment from not only their family, but also their community regarding their caregiving. Most participants struggled with taking care of a relative with severe Alzheimer's Disease and were still able to maintain their patient and friendly attitude day by day, even in chaotic situations. However, screaming, crying, and yelling at the care recipients were also found as common reactions of caregivers when dealing with their loved ones with disruptive and violent behaviors. The neighbors and other people in the community with limited understanding of dementia tended to criticize and judge caregiver participants for their frustrating reactions. Labels, such as 'a terrible wife' created a psychological barrier to participants to endure their caregiving duty. Caregivers adopted social pressure and judgment from their family and community, and internalized them to create their own judgmental standards which they used to judge themselves. A female caregiver was open about her struggle with the judgements from her neighborhood:

*Neighbors around here, when they heard me yelling at my husband, they thought I treated him badly, they thought this and that. For example, they thought I was disrespectful to him. Sometimes I told myself: "Ignore them, let them judge. I do not have to care to cause myself a headache." But I often have to deal with it. [Crying and coughing] I am angry when they judge me like that. They talked behind my back then it came back to me. I just wanted to tell them that no one wanted to be like that. It is difficult to explain for myself. (CG05, Female, 71)*

Social pressure and judgment mostly reported by female caregivers reflects typical gender norms in Vietnam. In the context of a Confucianism-based culture, women are expected to take a good care of the whole family. Vietnamese daughters and daughters-in-law often struggle with maintaining multiple roles, such as taking a good care of the sick parents, nurturing and teaching children, doing chores, and contributing to the household income if possible (Meyer et al., 2015; Truong, 2015). Under the pressure of leading multiple roles, caregivers desired understanding and support from other family members (Meyer et al., 2015). Despite some support from their spouses, siblings, or other relatives, family conflicts regarding care management likely cause more distress for primary caregivers (Meyer et al., 2015). These pressures and conflicts lead to caregivers' maladaptation, as well as poor physical and mental health, such as fatigue and resentment (Meyer et al., 2015).

### **Summary of the results**

The study explored perceptions of dementia, caregiving, and facilitators and barriers to adaptation to the caregiving role among Vietnamese family caregivers using the constructivist grounded theory approach. The study results report the belief system, as well as caregiving practice of participants regarding dementia care for their relatives based on their complex culture. Their belief system shapes their caregiving practice, including role taking and maintaining. *Figure 2.1* summarizes the results of this study.

The study results show that Vietnamese family caregivers' cultural foundation critically shaped their beliefs and perception of dementia, caregiving, and factors influencing their caregiving. These beliefs and perceptions were associated with each other, and together directed caregiving practice of the caregivers, including how they

took in and maintained their primary caregiving role. Participants in the study shared the same core cultural values of filial piety (among children caregivers), and affection and gratitude (among spousal caregivers), as well as moral standards of caregiving for their loved ones. These cultural values and moral standards were rooted in the traditional Confucianism which highlighted familism, and Buddhism beliefs which highlighted karma, or good deed sowing and reaping. In addition, the cultural foundation influenced structural factors in caregivers' lives, including their social support, as well as social pressure and judgments. Social pressure and judgments were formed in caregivers' families and communities based on their role expectation and social norms. Female caregivers, who undertook multiple social roles, such as daughter, daughter-in-law, wife, mother, and employee, perceived considerably high pressure and frequent judgment due to the expectation of a traditional standard moral daughter/daughter-in-law/wife, and family harmony and bonding. Caregivers' beliefs at both personal and structural levels motivated them to take on and maintain the role of primary caregiver no matter how burdensome the role could be. In short, providing care for a relative with dementia was perceived a way for family caregivers to live up to their culture-based belief system and moral standards, as well as to fit in the social expectation associated with their roles.

## **DISCUSSION**

Culture critically matters in understanding human experience of illness and caregiving (Kleinman & Benson, 2006; Kleinman, Eisenberg, & Good, 1978). Culture shapes health beliefs, values, emotional and behavioral reactions of patients and their family caregivers. The results in this study reflect the importance of culture in shaping

Vietnamese family caregivers' perceptions of dementia, caregiving, as well as facilitators and barriers to their adaptation to caregiving role for relatives with dementia.

First, culture explains Vietnamese family caregivers' perspective on dementia. In this study, caregivers consistently used terms, such as '*being confused*,' '*forgetful*,' and '*absent-minded*' to label dementia symptoms. In terms of what caregivers believed to be the causes of the disease, most respondents approached dementia from the perspective that considered dementia a consequence of the aging process, with some referring to '*normal aging*,' and others to '*poorly aging*.' They also linked dementia to physical conditions, such as insomnia and poor nutrition, as well as psychological traumas or distress, such as loss, grief, depression, and PTSD. Their explanations of dementia are mostly based on their mixed beliefs between folk and biomedical approaches.

Scholars introduced different explanatory models of dementia (Downs, Clare, & Mackenzie, 2006; Innes & Manthorpe, 2013; Kleinman et al., 1978; McCleary & Blain, 2013). Among the introduced models, biomedical and folk models (Kleinman, Eisenberg, & Good, 1978) are the most popular explanatory models adopted in dementia care (Hinton et al., 2008; McCleary & Blain, 2013). In the biomedical model, dementia is approached as a pathological, abnormal condition which is "*organic in etiology and progresses through stages*" and "*diagnosable using biomedical assessments*" (Innes & Manthorpe, 2013, p.684). The biomedical model is dominantly adopted among people with higher education in developed countries (Kleinman, Eisenberg, & Good, 1978). Asian caregivers tend to use folk or mixed models instead of biomedical model to explain the symptoms and causes of dementia, such as a normal aging process (Hinton et al., 2005; McCleary & Blain, 2013). Vietnamese family caregivers in this study, like



Vietnamese immigrants, already learned about the diagnosis of dementia from the hospital, still heavily leaned on the mixed model to make sense of dementia (Hinton et al., 2005).

Second, culture also plays a key role in shaping Vietnamese family caregivers' perception of caregiving and perceived facilitators and barriers to their adaptation to the caregiving role. Data analysis in this study shows that cultural foundation of Vietnamese family caregivers was built upon Confucianism and Buddhism. All caregivers in the study upheld the key values of filial piety, affection and gratitude associated with family cohesion. They also emphasized their moral standards in taking in and maintaining the responsibility of caregiving based on their beliefs of karma or good deed sowing and reaping. This is supported by Miyawaki (2015) whose study finds out that filial responsibility, reciprocity, and familism are the three key cultural values across Asian family caregivers, including Vietnamese.

Vietnamese family caregivers in this study consistently emphasized the importance of family harmony and cohesion, or emotional bonding among family members (Olson, 1999), as the motivators to their caregiving. This maps on the concept of familism in caregiving (McCleary & Blain, 2013). McCleary and Blain (2013) introduce three sub-components of familism, including family obligation, family support, and family as referents for expected moral behavior so as to avoid negatively impacting family reputation. To be specific, each family sets up its moral standard and sub-culture of reciprocal care among its members. Each member is obligated to provide care for the sick ones with the expectation of receiving support from others when needed (McCleary & Blain, 2013). Participants in this study reflected upon their participation in caregiving

as a mean to fulfill their designed role and meet the expectation from their family and community. On the other hand, caregivers also expected support from their family as an evidence of their family cohesion. As a result, family caregivers found it a critical facilitator when they received adequate support from their family. Those who received no or limited support from their family considered it a barrier to the successful adaptation to their caregiving role. They also associated this barrier with negative emotions, such as disappointment, anger, and resentment because the lack of family support implied that their belief system in family cohesion, or familism, had failed them.

Last but not least, the consistency in perception of dementia and caregiving, including the use of dementia terms, and the mixed model combining both folk and biomedical approaches, used by participants in this study and Vietnamese immigrants in previous studies is likely rooted in the shared culture of caregivers. Mchitarjan and Reizenzein (2015) suggest that culture-transmission motive fosters immigrants to maintain their own mother-tongue language as a reaction to the threat of language loss. The maintenance of the Vietnamese language, including their terms of dementia, in dementia care reflects the importance of culture in Vietnamese caregivers' health beliefs, despite their geographic locations (Innes & Manthorpe, 2013).

## **LIMITATIONS**

Although this study contributes to the knowledge of Vietnamese family caregivers of people with dementia, this study has limitations. First, the sample of caregivers in the study is limited. This study collected data from 20 family caregivers whose relatives were clinically diagnosed with dementia at the NGH. Due to the setting, sample size, and sampling method, the sample likely refers to a homogeneous group of participants which

restricts the generalizability of the study results to Vietnamese family caregivers in general. However, with the exploratory nature of the study, the results will contribute to a primary understanding of culture-grounded experience of Vietnamese family caregivers regarding their care for relatives with dementia.

Second, the selection of only primary caregivers from the North of Vietnam draws to another limitation of the study. Caring for older adults with dementia is usually a complex duty that may be shared by different caregivers in the same family, such as adult daughter, daughter-in-law, spouse, and others. This study, however, targets only primary caregivers as informants. In fact, in some families, multiple members all consider themselves primary caregivers. Besides, caregiving practice is likely different across regions of the country (Dam et al., 2006). As a consequence, the results cannot take into account perception of other family caregivers, such as secondary or other caregivers. On the other hand, having a small sample size of a homogeneous group of primary caregivers enables us to reach theoretical saturation (Guest et al., 2006).

Third, language translation is often considered a limitation in studies that take into account sociocultural factors. In this study, participants were interviewed in Vietnamese. It is challenging to adequately translate some terms or sayings rooted in traditional Vietnamese culture, such as ‘*being confused/confusing mind*’ (*lẫn*) and ‘*tình nghĩa*’ (*affection and gratitude*). With the support of the dissertation committee which consists of two Vietnamese American researchers, this paper is expected to introduce the results with the culturally-rooted terms as the most accurate and translatable as possible.

## CONCLUSION AND IMPLICATIONS

Existing literature exposes a large gap in the knowledge of caregiving in the sociocultural context of Vietnam. As part of a larger study on different aspects of caregiving experiences in dementia care of Vietnamese family caregivers, this paper provides updated and context-grounded results of caregivers' current perceptions of dementia and its causes, caregiving, and facilitating and inhibiting factors to their adaptation to the caregiving role. The results reflect upon the importance of culture in shaping Vietnamese family caregivers' perception of dementia and caregiving, which direct them in their caregiving practice.

This study extends the scant literature on perception of dementia, caregiving, and influential factors on caregiving of Vietnamese family caregivers, and implies the need of further studies with larger sample sizes and more diverse participants and settings. As the study results suggest, Vietnamese family caregivers shared their culturally-shaped perception of dementia and caregiving. However, their perception of caregiving, particularly regarding the use of nursing home and other social supports, has been changing. This result asks for more studies to explore the changing trends in family caregivers' mindset and care decision-making. Further studies are also much needed to deepen the understandings of caregivers' perception of facilitating and inhibiting factors to their caregiving role in a changing context.

Moreover, the study results yield practical implications for the roles of social workers to support Vietnamese family caregivers for older adults with dementia. Vietnamese family caregivers dominantly used the mixed model combining folk and biomedical approaches even after learning from the diagnosis of dementia at the hospital.

Even adopting the mixed model, their perception heavily leaned on the folk beliefs in explaining the causes of dementia. This fact implies that social workers need to collaborate with health professionals to better understand, communicate with, and educate family caregivers. The study results also contribute to policy advocacy targeting family caregivers in the Vietnamese social welfare system. Until now, there is no policy or social service for family caregivers in the formal social service system in the country. Along with the rise of social work profession in Vietnam, social work is expected to contribute to the area of older adult care and family caregiver support. This study, therefore, will contribute to the development of social work scholarship targeting these underserved populations.

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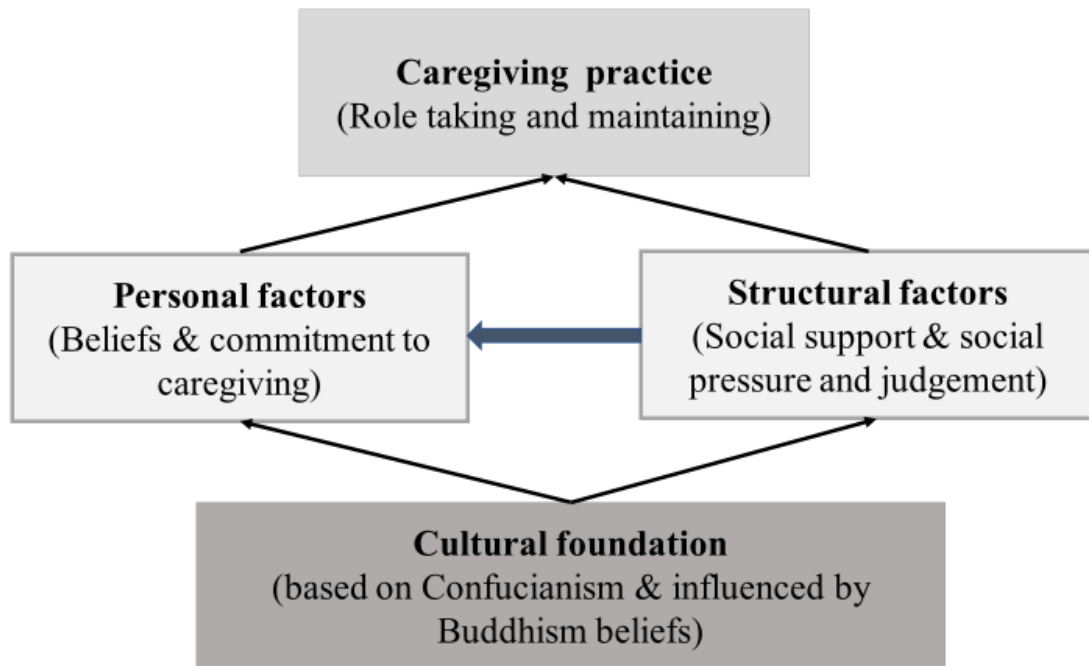
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Table 2.1

Characteristics of caregivers and care recipients

Characteristics	Caregiver participants (N = 20)		Care recipients (N = 19)	
	n	Mean (Range)	n	Mean (Range)
Gender				
Male	7		11	
Female	13		8	
Geographic area of residence				
Rural area	7			
Urban area	13			
Educational level				
Primary school	1		5	
Secondary school	4		5	
High school or Vocational school	5		3	
College or higher	10		6	
Job				
Retired	13			
Farmer	3			
Public officer	3			
House-maid	1			
Marital status				
Married	18			
Single/Divorced/Separated	1			
Widowed	1			
Relationship with CR				
Spouse	13			
Daughter	4			
Daughter-in-law	1			
Son	1			
Son-in-law	1			
Number of people in the household		4 (2 – 10)		
Age		61 (34-86)		73 (57 - 88)
Hours of caregiving per day		7 (3-8)		
Estimated years of dementia exposure				5 (1 – 20)
Estimated months of treatment in NGH				30 (1 – 96)



*Figure 2.1* Culture-based perception of dementia and caregiving among Vietnamese family caregivers

## CHAPTER 3

### PAPER 2: HELP-SEEKING PERCEPTIONS AND PATTERNS OF VIETNAMESE FAMILY CAREGIVERS IN DEMENTIA CARE<sup>2</sup>

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<sup>2</sup> Nguyen, T. Help-seeking perceptions and patterns of Vietnamese family caregivers in dementia care. To be submitted to *Journal of Applied Gerontology*.



## **Abstract**

This paper aims to explore help-seeking perceptions and patterns of Vietnamese family caregivers for older adults with dementia. Using constructivist grounded theory, 20 Vietnamese primary family caregivers were interviewed face-to-face. A total of 30 interviews, including 10 follow-up interviews, were conducted. The help-seeking process related to caregiving demands of Vietnamese family caregivers consisted of four stages: (1) Disease and caregiving experience; (2) Cognitive appraisal; (3) Action; and (4) Outcomes. Caregivers highly valued independence and autonomy in caregiving, and self-sacrifices and devotion to family. They sought help only after acknowledging that they could no longer handle caregiving responsibilities by themselves despite their efforts. The most common demands for which caregivers sought help included seeking information for medical decision-making, interpersonal communication, task sharing in hands-on care, caregiving emergency (e.g., hospitalization), and finding time for self-care. After identifying the problems, they matched them with feasible formal (hospital) and informal sources (family, neighbors) available in their social network. Their help-seeking perception, strategies, and process reflect their complex Confucianism-based culture with multiple religious and spiritual strands.

## **Keywords**

Dementia; Alzheimer's Disease; Vietnamese family caregivers; help-seeking; grounded theory

## INTRODUCTION

Providing care for a family member with chronic diseases is challenging. It constantly puts family caregivers in the situations that require them to decide whether they may need to seek help to meet the caregiving demands. Help-seeking behaviors refer to how family caregivers cope with their care-related problems using their resources and interpersonal communication to mediate the adaptation outcomes (Cornally and McCarthy, 2011; Lazarus & DeLongis, 1983; Lazarus & Folkman, 1984). Help-seeking behavior is a complex social construct referring to both a process and style (Cornally & McCarthy, 2011). As a process, help-seeking behaviors refer to a complex decision-making process which consists of consequential stages to solve the problems (Cornally & McCarthy, 2011; Levkoff et al., 1999). As a style, help-seeking behaviors are concerned with the preferred sources of the help, including formal and informal sources (Cornally & McCarthy, 2011). Besides, Levkoff et al. (1999) emphasize the importance of culture, particularly religious and spiritual beliefs, in understanding help-seeking behaviors of the diverse populations, such as Asians.

The purpose of this paper is to explore help-seeking perceptions and behavioral patterns of Vietnamese family caregivers for relatives with dementia. This paper is the second of the trilogy on caregiving experiences of Vietnamese family caregivers in dementia care. Connecting to the first paper on Vietnamese family caregivers' perception of dementia, caregiving, and influencing factors on their caregiving, this paper focuses on help-seeking perceptions and strategies which primary family caregivers applied in the process of providing care for their relatives with dementia in their context in Northern Vietnam.

The Vietnamese government has been recently concerned with the rapid and significant increase of older adult population which refers to people aged 60 and above (Tatarski, 2016; United Nation Population Fund [UNFPA] Vietnam, 2010, 2011). The number of Vietnamese older adults is projected to go up from 10.45% of the population (approximately 9.5 million people) in 2014 to 30.8% in 2050 (General Statistics Office & UNFPA, 2016; HelpAge Global Network, n.d.). Aging is associated with the prevalence of chronic conditions, including dementia - one of the top-rated health burdens in Vietnam (Bang et al., 2017; Truong, 2015).

In Vietnam, providing care for an older adult with dementia is primarily undertaken in the family unit (B. N. Nguyen et al., 2013; Truong, 2015). This caregiving practice reflects the culture and context of Vietnamese families. Vietnamese people highly uphold their Confucianism-based culture and its values, such as filial piety and familism (Dam, Tran, Duong, Khuong, & Nguyen, 2009; Truong, 2015). Besides, the social policy system, which is strongly influenced by the traditional Vietnamese values, also emphasizes the role of family in providing care for older family members. To be more specific, Article 10, Section 1, Chapter 2 in the Law on the Elderly states that children, grandchildren, and other relatives are responsible for caregiving for older members when they are sick (Vietnam National Assembly, 2010).

Vietnamese family members tend to take on the role of the caregivers for their relatives with dementia without much intention of help-seeking from outside of their family for multiple reasons. First, the traditional Vietnamese culture suggests the family-centered approach in caregiving. Taking care of older family members is considered a common way to fulfill filial obligation and meet the Confucianism and Buddhism-based

moral standards of family cohesion and good deed sowing and reaping (Dam et al., 2009; B. N. Nguyen et al., 2018; M. D. Nguyen, 1985; Truong, 2015). Second, limited knowledge of dementia, particularly with dementia being attributed to the normal aging process, often results in family caregivers not seeking medical help for their relatives from the formal systems, such as the hospital (B. N. Nguyen et al., 2018; T. B. Nguyen et al., 2018). Third, formal support systems, including the professional healthcare services and community organizations, are extremely limited in Vietnam (B. N. Nguyen et al., 2018), with dementia diagnosis and treatment programs rarely existing at the community level. In addition, community health workers are overworked and not prepared with the education or skills to diagnose or provide basic medical treatment for older adults with dementia. Community organizations, such as the local association of older adults and veteran associations, do not provide any type of support for members with dementia or their families (B. N. Nguyen et al., 2018).

In short, a few existing studies discuss some aspects of the context and culture which contribute to shaping help-seeking behaviors of Vietnamese family caregivers, especially in the formal systems mostly in the north of Vietnam (B. N. Nguyen et al., 2018; T. B. Nguyen et al., 2018; Truong, 2015). In addition, some studies on the same topic were conducted with Vietnamese immigrants in the United States with the consideration of their acculturation stress (Braun & Browne, 1998; Braun et al., 1996; Levkoff et al., 1999; Liu et al., 2008; Meyer et al., 2015; Yeo et al., 2002). These studies focus on help-seeking behaviors of caregivers in the healthcare system for their relatives' needs. However, the specific perception, strategies, and process in which domestic Vietnamese family caregivers make decisions to seek help in their own context remain

unknown. Addressing this knowledge gap, this study aims to understand the complex help-seeking perceptions, strategies, and process of Vietnamese family caregivers to meet their caregiving demands in their context.

## **METHOD**

### **Research design**

This paper draws on a larger qualitative study on Vietnamese family caregivers. The study adopted constructivist grounded theory based on symbolic interactionist perspective (Charmaz, 1990, 2014). This approach shows its strength in exploring participants' unique experiences in their own context and culture through their perspectives (Carroll et al., 2007; Liu et al., 2014, 2015; McCalman et al., 2013; Mendez-Luck et al., 2016; Ononeze et al., 2009; Waterworth et al., 2016). As the study aims to understand Vietnamese family caregivers' help-seeking perception, strategies, and process in dementia care, this methodological approach is a suitable choice. Following the constructivist grounded theory approach, the data collection and analysis were conducted iteratively along with theoretical sampling and constant comparative method. This approach helps with data saturation for theory development of the help-seeking process (Charmaz, 1990, 2014; Ng & Hase, 2008).

### **Ethical consideration**

Prior to data collection, the University of South Carolina (USC) Institutional Review Board (IRB) approved the research protocol. In addition, the National Geriatric Hospital (NGH), where the participants were recruited, approved the research protocol in Vietnamese language. At the beginning of the first interview, a Vietnamese informed consent was distributed to and collected from each participant. Each participant was

assigned an identification number while their identifiable information was removed from transcripts for their confidentiality protection. Only the researcher was preserved the access to the data in a secured folder on a laptop with a password.

## **Sample**

### **Setting**

The National Geriatric Hospital (NGH) was selected to be the primary setting where the participants were recruited. The NGH is located in Hanoi and well-known for being the only unit providing specialized geriatric care at the national level in Vietnam. The NGH was under the management of the Ministry of Health (MOH). The MOH operated the hospital system at the four basic levels, including precinct-, district-, provincial-, and national levels. For specialized geriatric services, older adults and their families would have to access the provincial hospitals. Even among the provincial hospitals, only 44% of the total 63 provincial hospitals across the country provided geriatric services (H. Nguyen, 2016). At the national level, the NGH has been the only unit targeting mental health care, particularly dementia care, for older adults.

The NGH operated a Dementia Program under the Department of Neuropsychiatry and Alzheimer's Disease. With four psychiatrists and 16 nurses/nurse assistants, the department provided care for approximately 130 out-patient every year (B. Nguyen, personal communication, March 19, 2017). The Dementia Program was funded by the Vietnamese government to provide affordable medical treatment for older adults clinically diagnosed with dementia and affiliated with public health insurance. NGH's health professionals diagnosed dementia with Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM IV TR; American Psychiatric

Association [APA], 2000). The key treatment provided by the Dementia Program was medication prescription and monthly check-up. Psychiatrists in the program often prescribed patients with medicines for dementia symptoms, such as Aricept and Razadyne (Galantamine) along with multivitamins. They also requested patients and family caregivers to visit the hospital monthly for the follow-up and medication refill. Being recruited in the government-funded Dementia Program, patients received from 50% to 100% of their medical bill coverage.

### **Participant recruitment**

Purposive sampling (Charmaz, 2014; Guest, Bunce, & Johnson, 2006) was applied to recruit participants as it was culturally appropriate and effective approach in the hospital setting. The psychiatrists and nurses in the Dementia Program consulted and supported the recruitment. They first sorted a list of current patients in the program with the contact information of their family caregivers. They then distributed the recruitment flyers to and collected contact information from interested family caregivers for the short list of the study. Using the short list, I contacted the interested family caregivers via phone calls to explain further about the study aims and procedure, as well as screen their eligibility for participation in the study. Totally 20 caregivers met the inclusion criteria as the follows: (1) be at least 18 or older; (2) self-identify as primary family caregiver who has provided direct, hands-on, and substantial day-to-day care (minimum 20 hours/week) for a family member clinically diagnosed with dementia; (3) have taken care of the relatives with dementia for at least one year consecutively; and (4) have no self-declared cognitive disability and can communicate in Vietnamese. These 20 caregivers were invited to choose their preferred time and location for the interview.

## Data collection

In order to test the feasibility and appropriateness of the interview guide, a pilot study with two interviewees were conducted. The two interviewees self-identified as caregivers of older adult with memory problems. These interviews were used to facilitate the revision of the interview guide only, and they were excluded from the data analysis of the study.

Post pilot study, totally 30 face-to-face, semi-structured interviews, including 10 follow-up interviews, were conducted iteratively with 20 participants at their homes or the hospital depending on their preferences. The duration of each interview varied from 30 to 97 minutes and on average, each interview lasted 58 minutes. With each complete interview, a participant received \$15 incentive.

Interviews were conducted inductively in Vietnamese language using the interview guide. Within the scope of the research questions in this paper, data collection focus on examining the attributes of help-seeking behaviors of Vietnamese family caregivers (what problems, whom, where, and when they seek help from), their perception of available social supports, how they make decisions in seeking help, and consequences of their help-seeking behaviors. In order to facilitate participants to express their perspective openly, the questions from the interview guide were probed flexibly depending on the flow of the conversation and previous response of the participant. A typical interview was started with broad, open-ended questions, such as: *“Tell me about your experience of living with/caring for your relative,”* followed by more detailed questions, such as:



- *What are your daily care routines? Or: Could you describe a usual day of you and your relative? Was there anyone helped you with these care routines? If yes, who were they? What and when did they often help you with care activities?*
- *Have you ever asked someone (your family, friends, neighbors, etc.) for help with care for your relative? What did you ask for help? What were the results? Were you satisfied with them?*
- *Do you know about any organization, agency, clinic, or professional in your community that you can ask for help regard your care for your relative? If yes, have you ever tried to ask any of them for help? What were the results? Were you satisfied with them?*

After signing the informed consent, all participants approved digital recording of the interviews for verbatim transcription. They also provided their demographic information at the end of the interviews, which were then removed from the transcripts and given input into a separate Microsoft Excel Sheet for data analysis purpose only. Observation, field notes, entry logs, reflective and analytic memos were also conducted during and after the interviews for data triangulation and analysis.

### **Data management and analysis**

As a constructivist grounded theory study, data collection and analysis were conducted iteratively using theoretical sampling (Charmaz, 1990, 2014; Corbin & Strauss, 2014; Creswell et al., 2007; Creswell, 2012). I started data collection with the first ten interviews with ten participants to explore initial codes and themes. During the time of these first ten interviews, I reviewed voice records, transcripts, and field notes of the interviews, as well as wrote reflective and analytic memos. This process helped me refine interview questions with new participants, as well as refocus and explore further initial codes and themes in the follow-up interviews with selected participants. Next, I conducted 20 more interviews, including 10 interviews with 10 new participants, and 10 follow-up interviews with eight participants from the previous round. Theoretical saturation was found when no new themes emerged from the data (Charmaz, 2014;

Corbin & Strauss, 2014; Creswell et al., 2007; Creswell, 2012; Guest et al., 2006; Ng & Hase, 2008; Strauss & Corbin, 1997). Considering this principle, in this study, the theoretical sampling process ceased after 30 interviews were completed.

Data, including Vietnamese transcripts, field notes, memos, and related documents were stored securely in a laptop with a password managed by the researcher only. Original Vietnamese transcripts were used for coding with the qualitative data analysis program MaxQDA 12. Coding original transcripts in Vietnamese language protected the linguistic and cultural authenticity of the data for internal validity improvement. Audited transcripts in which identifiable information of participants were removed were shared with the two Vietnamese-American members of the researcher's dissertation committee for validity checking purpose only. The two committee members randomly selected a few audited transcripts to examine the accuracy and cultural sensitivity of language transfer in data analysis and result interpretation. When there were disagreements in the language transfer, the researcher discussed with the two committee members till an agreement was set.

Data analysis of the transcripts were conducted using the qualitative data analysis program MaxQDA 12. The analysis procedure included three phases: (1) initial coding, (2) focused coding, and (3) theoretical coding (Charmaz, 2014). Initial coding helped me develop initial categories by working closely, yet openly with each line of the transcripts. In the focused coding phase, I compared data to detect the most used codes across transcripts. In the following phase of theoretical coding, I selected core categories based on the most used codes and integrated them into two umbrella categories, including

participants' perception of help-seeking in dementia care and their actual help-seeking behaviors and their results.

During the data analysis process, constant comparative strategy was used consistently with different sources of data for theoretical sorting and theory integration (Charmaz, 1990, 2014; Ng & Hase, 2008). This strategy was applied to compare within transcripts, and memos. In addition, results of participants' help-seeking perception and behaviors emerging from the data were compared with relevant literature.

## **RESULTS**

### **Participant characteristics**

A total of 20 participants, including seven males and 13 females, aged from 34 to 86 (mean = 61) participated in the study. Two third of the participants lived in urban area. While a half of the participants had their highest educational level as high school or lower, the rest of them held a college degree or higher. Regarding their employment status, 13 participants retired; seven were working full-time as public-sector officers (n = 3), farmers (n = 3), or a paid house-maid (n = 1). Except for a widow and a female participant who was separated from her husband, other participants were married and co-residents with their spouses. On average, each participant spent seven hours (ranged from three to eight hours) every day to take care of their relatives, who were either their spouses (n = 13), parents (n = 5), or parents-in-law (n = 2) (*Table 3.1*).

The 20 participants in the study were taking care of 19 care recipients with Alzheimer's Disease in the Dementia Program during the time this study was conducted. Two participants, including a son-in-law and a wife, were taking care of the same care recipient and both considered themselves primary caregivers of the care recipient with

different duties, such as activities of daily living (ADLs) care or healthcare-related decision making. The care recipients included 11 males and eight females, aged from 57 to 88. Based on the recall of caregiver participants, the care recipients showed the first symptoms of dementia for at least a year and the average time of living with dementia was five years. The average length of time a care recipient had been in the Dementia Program was 30 months (ranged from one to 96 months). Their educational level varied from high school or lower (n = 13) to college (n = 6).

### **Overview of the help-seeking model**

Family caregivers went through different stages to seek help for their caregiving demands. *Figure 3.1* depicts the help-seeking process which family caregivers experienced to meet caregiving demands. Their iterative help-seeking process consisted of four stages, including: (1) Disease and caregiving experience; (2) Cognitive appraisal, including primary and secondary cognitive appraisal; (3) Action; and (4) Outcomes. Family caregivers took care of their relatives through different stages of the disease process.

Family caregivers experienced different types of symptoms. A few care recipients were at the beginning stage with mild cognitive changes, manageable behaviors, and high level of independence in ADLs. Some other care recipients needed much more attention, supervision, and hands-on care from their family caregivers. For example, some care recipients showed extremely disruptive behaviors, such as wandering and unmanageable toilet behaviors. That said, family caregivers experienced different situations which contributed to their help-seeking decision.

Following unique experiences of Alzheimer's Disease's symptoms and illness management, family caregivers went through different levels of their cognitive appraisal. Participants exposed different styles and variances in their perception of help-seeking in their cognitive appraisal. At the level of *primary cognitive appraisal*, family caregivers examined their situations to decide whether they needed to seek help from someone else. As primary caregivers, participants tended to refuse to seek help when they perceived that they were still able to manage the situation themselves (self-sufficiency situations). Participants only sought help for the problems, demands, or situations they considered 'out-of-hand,' such as medical issues. Participants also asked for assistance with short-term, temporary issues. For example, a participant would ask her relative to stay with and supervise the care recipient for a few hours when she traveled shortly to the hospital to pick up medication refill.

At the level of *secondary cognitive appraisal*, family caregivers clarified their target problems and feasible sources for help-seeking strategy. The secondary cognitive appraisal significantly contributed to shaping caregivers' help-seeking. For a defined demand, each participant accessed feasible sources available within their social network. The outcomes of help-seeking actions played a part in shaping participants' caregiving experience and refining their upcoming help-seeking strategies. For instance, a participant decided not to ask for help from her relatives again when she experienced their refusal of task sharing in caregiving for her mother-in-law. She also experienced social isolation and psychological distress stemming from this outcome of her help-seeking.

### **Perceptions and strategies of help-seeking in self-sufficient situations**

Following the stage of disease and caregiving experience, family caregivers proceeded to the stage of cognitive appraisal, which first they assessed whether they need to seek help. Family caregivers assessed whether a situation was self-sufficient using their two-level judgment. First, they judged from within the ‘*self*’ of a caregiver to weight the key values of independence, autonomy, devotion, and self-sacrifice over the situation. Second, they judged from within their family unit to see if the self-reliance regime of the family adequately provided voluntary support for them to ease from asking for extra help. A self-reliance regime referred to the voluntary and willing support that members from nuclear and extended families provided to the primary caregivers in dementia care. Using the two-level judgment, family caregivers tended to delay their help-seeking as long as the situations were perceived as under control and self-reliant. In most cases, participants considered the situation self-sufficient when care recipients’ symptoms were manageable with mild cognitive changes, higher independence in ADLs, and minimum disruptive behaviors.

#### **From within the self: Independence, autonomy, devotion, and self-sacrifice**

Although participants were from different socioeconomic backgrounds and caregiving situations, they all shared the key values of independence, autonomy, as well as devotion to their family, and self-sacrifice. First of all, family caregivers highlighted the importance of independence and autonomy in caregiving as they associated these values with their identities as primary caregivers. They, therefore, preferred to undertake caregiving duties as much as they were ‘*able to*’ or ‘*still capable of*’ (carrying out caregiving duties). Asking for help, therefore, was perceived as ‘*bothering others*,’ ‘*being*

*dependent,’ and ‘becoming a burden.’ A spousal caregiver commented: “It is just my personality. I honestly do not want to bother my children. I try as much as I can (to take care of the husband). I am the person who does not want to bother anyone or become a burden to anyone.” (CG05, Female, 71).*

To many participants, being a primary caregiver implied both a privilege (or pride) and a challenge. To older, and usually spousal caregivers, undertaking the role of a primary caregiver represented their values in the family as a worthy and helpful member. The majority of the spousal caregivers were retired and lived on their limited retirement pensions. Many of them relied on their children’s financial support to cover the medical treatment for their loved ones. As they could no longer contribute to the household income, spending time taking care of the care recipient was considered a method of contribution to the whole family. As a result, these caregivers delayed their help-seeking behaviors as long as possible. Instead, they preferred to ‘*keep trying*’ to maintain all caregiving duties by themselves to prove their capacity and values. A male caregiver commented that he would ask his adult children for help with caregiving only when he “*cannot do that anymore, cannot even walk or crawl.*” (CG03, Male, 86). He emphasized that he did not want to bother or even trust anyone else, except for himself, to provide the best care for his wife.

In addition to the upholding of independence and autonomy, participants shared their values of devotion to their loved ones and self-sacrifice in caregiving which also hindered their intention to seek help. These values were rooted in participants’ Confucianism-based traditions of filial piety, familism, and selfless actions, which encouraged participants, especially women, to put others in their family first, particularly

older members (Miyawaki, 2015). Many participants shared the belief that they were the best fit for the caregiving role, and caring for and serving others were their mission in life. This perception was particularly common among female caregivers, as a daughter-caregiver noted:

*Whatever I can help, I will help. I do not give a second thought about it. I just help people. It is the way of life. I never think that people owe me anything if I help them. Even in my family, I help my siblings, my parents. My siblings pity me: "You are a woman, but you have to take care of everything." But no, I do not think that. I just think it (caregiving) is my responsibility rooted in my conscience. Whatever I can do, I will try my best. After those events (taking care of relatives in the hospital), I had to buy myself medication and supplements. I knew I felt unwell and I needed to take care of myself. Sometimes, I met with doctors for their advices, then I took care of myself. I did not bother anyone else. I am not the type of person who likes to complain, even when I feel like I am about to collapse. Like when I took care of my siblings, I felt like I was about to pass out, but I did not say anything because my ill relatives needed me. I knew they would have been scared if I left them, so I did not want to show anything. (CG09, Female, 54)*

Culture, including gender norms, and personal history contributed to caregivers' devotion to their family members, self-sacrifice, as well as self-trained and self-discipline of female caregivers in their caregiving practice and help-seeking intention. Many caregivers experienced different adversities in the past, which contributed to develop their resilience to cope with constant challenging situations. Besides, these values were associated with their social roles and corresponding social expectations of their roles. For example, a daughter-caregiver revealed: *"After the treatment (of depression), I trained myself because I could not lean on anyone. My children were too young, my parents needed me as I was the oldest daughter in the family. I could not keep asking my brothers-in-law for help."* (CG10, Female, 44). Family caregivers, like this participant, tended to internalize social expectations associated with their role, including gender norms, to set up their own standards of devotion and self-sacrifice in caregiving. Female



members, such as the oldest daughter in the family, often upheld high standard in providing care to the care recipients with dementia, along with fulfilling other role demands, such as a devoted wife and mother, and a hard-working employee. This reflected culturally predetermined self-contract of caregivers to their social roles in their families and communities, and hindered help-seeking intention of participants.

### **From within the family: Self-reliance regime**

Family caregivers assessed whether a situation was self-sufficient or not based on not only their judgment from within the ‘*self*’ of a caregiver, but also from within their family regime. Caregivers in this study differentiated the effort and action of asking for help between the contexts of no pre-established and already established task-division regime within the family. For caregivers who already received constant, voluntary support in caregiving duties from their family based on the natural task-division regime in their families, it was unnecessary for them to ask for help for caregiving duties. In other words, other family members initiating their participation and responsibility sharing in caregiving duties eased primary caregivers from verbally asking for help for caregiving activities within the regular routine.

Each caregiver’ family had its own dynamic and caregiving regime. Task division was arranged and agreed upon in participants’ families depending on the bonding and cohesion of the family, as well as the severity of care recipients’ condition. Family cohesion refers to the emotional bonding among family members (Olson, 2000). Many of the primary caregivers already set up a caregiving routine and task division with other family members in order to guarantee the best care for the care recipients. Among adult child caregivers, the oldest child often undertook the duty of “*coordinating and dividing*

*the tasks.*” In response, family cohesion and individual commitments fostered each family member to carry out their tasks properly. As a result, caregiving routine and interpersonal communication related to caregiving were carried out ‘*smoothly*’ which eased primary caregivers from asking for help from outside sources:

*We discussed together and took turn to take care of our father in the hospital. When we took our shifts, we discussed how we would take care of his diet, sleeping habit, and memory exercises. He had dementia, so he was slow and could not recognize things or communicate well. That was why we agreed to keep talking to him, telling him about our old memories. We also updated him about our current lives. (CG15, Female, 51)*

The self-reliance regime, which contributes to delay help-seeking behaviors among the primary caregivers, is culturally rooted in filial piety and familism in Confucianism (Miyawaki, 2015). Participants shared the belief that caregiving for an older parent with Alzheimer’s Disease was primarily family responsibility and a priority for children, as a male caregiver shared: “*We are thankful for still having our parents. If our parents pass away, we will have no one to visit anymore.*” (CG07, Male, 47). In addition, caregivers referred to not only their nuclear family, but also their extended family. To many caregivers, particularly those who lived in the rural areas, they received considerable social support from their children, older parents, siblings, siblings-in-law, uncles, aunts, nieces, and nephews. In this large caregiving network, it was quite common that all family members non-verbally agreed on their responsibilities and obligations in caregiving based on their solid family cohesion. As a consequence, they voluntarily played their role as secondary caregivers or temporary helpers without being asked:

*Caregiving is the shared responsibility of all children and grandchildren, sometimes it involved the neighbors. Siblings and other relatives (are all involved). When my relatives have something good, they all bring them to my mother. They take care of her meals. They volunteer to do that, no discussion for task division is needed. (CG01, Female, 56)*

Family harmony and cohesion are heavily weighted in the value system of Vietnamese family caregivers. They become not only a pride, but also a moral standard for family caregivers, particularly for adult child caregivers. From their perspective, these values surpassed the values of success and social title. They developed a set of criteria based on familism to approach and place their judgment on daily life situations, such as caregiving practice in other families. A daughter-caregiver commented:

*I think that even though my mother is sick, she has her children, including her sons, daughters-in-law, daughters, sons-in-law, to visit her. There are some patients sharing the same room with her in the hospital. They have children with fancy titles, such as doctors working at very big hospitals, but their children did not take care of them. Their children hired a maid to come and take care of them in the hospital. I feel so pity for them. Just look at them, they have money and successful children, but only a hired maid to take care of them. They look so miserable. The maid yelled at the old lady because she ate slowly. When I take care of my mother, I am always gentle to her. I do not want my mother to feel uncomfortable and just want to do the best to help her feel good and happy. (CG09, Female, 54)*

Having constant, voluntary participation in caregiving for the loved one with dementia from all family members served as an indicator of social pride and status of the caregiver, as well as family reputation (saving face). Many of the caregivers proudly expressed: “*It is my family tradition of having everyone contributing to caregiving!*” In other words, being able to refrain from asking for help from outside of the family was perceived as a pride and success of a cohesive family. This perception was more common among family caregivers living in the rural areas with a long tradition of mutual support among the extended family. Caregivers living in the urban areas often reported much smaller caregiving network within the family, as well as less constant and voluntary family support in hands-on care due to the busy urbanized lifestyle. These caregivers,

therefore, tended to be more open to seek help than those with the self-reliant family regime in the rural areas.

### **Perception and strategies of help-seeking in out-of-hand situations**

Primary caregivers tended to seek help only when they considered the situations out of their capacity to handle themselves. Those so-called ‘*out-of-hand*’ situations referred to the situations which primary caregivers lack caregiving knowledge or skills and/or when they needed short-term, temporary assistance for hands-on, direct care. ‘*Out-of-hand*’ situations occurred most often in people with advanced Alzheimer’s Disease. The care recipients in these cases were long-term patients with moderate or severe cognitive impairment, frequent disruptive behaviors, and high dependence in ADLs. They tended to show problematic behaviors, such as wandering, hoarding, uncontrolled toileting, and violently attacking others. In these situations, primary caregivers identified the problems they needed to seek help for and matched them with feasible sources available in their social network.

### **Clarifying targeted demands/needs**

*Need for information for decision making in medical care.* Information for decision-making in medical care was the most concerning issues among caregivers. Only a few primary caregivers at high educational levels held relatively substantial knowledge and skills in dementia care. The rest of the participants revealed that they had very limited understanding of dementia, as well as medical knowledge for caregiving decision-making for their relatives. As a consequence, most of the participants did not feel confident to make any medical-related decision before consulting with healthcare professionals, other family members, and friends. Information and advice seeking,

therefore, was the most common need in help-seeking among Vietnamese primary caregivers. For instance, a spousal caregiver was concerned about her husband's health condition, such as losing appetite, spitting, and having diarrhea, after taking the new medication from the hospital. She decided to stop her husband's medication after consulting with one of her sons-in-law. Even though this caregiver had thought about discontinuing the use of the medication, she only felt comfortable with the decision after receiving help from other family member.

*Need for assistance with interpersonal communication.* Many participants also revealed their need of help with interpersonal communication with healthcare professionals and the care recipients. Older female caregivers with lower educational level often felt unconfident in communication with healthcare professionals. They assumed that their low educational background hindered the transparency and effectiveness of the information exchange between them and the doctors. Thus, many caregivers preferred to ask their adult children with higher educational background to communicate with doctors and other service providers. Besides, they sometimes requested help from other family members to persuade care recipients in some specific situations, such as going to the hospital for health examination and hospitalization. For example, a participant who was a primary caregiver living in a mountainous area asked her daughter, a police officer, to meet with the doctor at the local hospital for her husband's transfer. She also asked another daughter to talk to her husband to convince him to go to the hospital. As she commented: "*We have to find the right person*" to achieve the communication goals.

***Need for task sharing in hands-on care.*** Even though primary caregivers tended to carry out most of the direct, hands-on care by themselves, they often needed temporary assistance in out-of-routine caregiving activities. As many caregivers played different roles in their family and workplace, they were not able to stay with and supervise care recipients 24 hours a day. Participants shared that when they had to take care of other responsibilities, such as going on a business trip, participating in some social events at the office or in the community, they often asked other family members or their in-home maid, if available, for short coverage. To participants with a large family network supporting their caregiving, they did not confront difficulty asking for help in those situations. Instead, they had multiple sources within their extended family to ask for help. A daughter-caregiver listed her husband and sisters as the frequent helpers to take their father to the hospital when she was busy with teaching. Requesting help for hands-on care, however, was time-limited. Participants highlighted their role of primary caregivers, and as a result, they did not request help from other family members unless they could not handle the task within their time frame. The daughter-caregiver emphasized: *“I was still in charge of caregiving coordination and task division. I planned carefully and then communicated with others.”* (CG15, Female, 51). In other words, remaining independent and proactive was important for the primary caregivers to fulfill their role and its associated social expectations.

***Need for assistance with caregiving emergency.*** As caregivers upheld their values of independence, autonomy, devotion to their loved ones, and self-sacrifice, they did not seek help frequently unless they could not control the situation. Caregiving emergency, such as hospitalization of the care recipients, was considered one of the

priority issues for which primary caregivers sought help. A spousal caregiver recalled the situation when her husband was hospitalized, and she had no other choice except for asking her children for immediate support:

*In the situation of my family, when my husband needs to be hospitalized, my children have to take him there. But it would affect my children a lot because their jobs are very demanding. My children work abroad, their working pressure is very high, and they do not have much time. They work from early in the morning till late at night, from 6:30 or 7:00 am to 7:00 pm. When they have to help me with their father's hospitalization, they have to ask for absence from work. Every time my husband was hospitalized, they all had to do that. (CG12, Female, 68)*

Even in the tough situations like this, the primary caregivers still tried to remain independent as much as possible. They maintained their leading role in caregiving and spent the most significant time in the hospital with care recipients. They asked for help from others in order to better control and manage the chaotic situations. Secondary caregivers and other helpers often reduced or ceased their help when the conditions of the care recipients improved in the hospital.

***Need for self-care.*** Primary caregivers in different situations reported different opinions on self-care. Novice caregivers for a person with dementia at the beginning stage of Alzheimer's Disease did not experience many changes in their usual lifestyle, and as a result, they did not struggle with finding time for self-care. In contrast, long term, experienced primary caregivers caring for persons with advanced Alzheimer's Disease revealed more pressing need for self-care. However, they were socially restrained by the demands of caregiving. Seeking short term help for a certain amount of time became one of the possible solutions to many participants. Some of them with adequate financial resources decided to spend extra money seeking help from in-home maids in order to gain personal time for themselves.

*I have just hired a new maid because I need to go out sometimes. I cannot keep staying home 24/7 with him like this. If I keep doing that, I will collapse. That is why I decided to hire a maid, even though it is not easy for me financially. Both he and I receive under seven million Vietnamese Dong (US \$350) per month for retirement pension. My children help out a little bit. They are public-sector officers, they do not have much to support me. But we try. At least with the help of a maid, I can get out of the house to exercise and see other people. Every morning, I practice Tai Chi. I also practice in the afternoon with other members in the Women Club in the precinct. Each session lasts an hour, that means I practice two hours every day. (CG14, Female, 70)*

Asking for help for self-care was found only among older caregivers who had devoted years of their lives to providing care to their loved one with advanced Alzheimer's Disease. As these caregivers strictly upheld the values of independence, autonomy, devotion, and self-sacrifice, they tended to carry out their primary caregiver responsibility mostly by themselves for years. The turning point leading to their request for extra help to reclaim time for self-care often happened only when they burned out and clearly acknowledged their physical and psychological limits.

### **Identifying feasible sources for help**

After clarifying the targeted needs, caregivers identified feasible sources available for their help-seeking. Social networks of participants were different, so were their available sources for help-seeking. Feasible sources for help-seeking included both formal and informal sources. Formal sources referred to healthcare providers at the NGH and other healthcare and social services. Informal sources consisted of family, friends, neighbors, hired house-maid, and religious/spiritual facilities. It is worth noticing that not all caregivers could be able to access to all of these sources.

**Formal sources.** As all participants were recruited from the NGH, it is understandable that the most commonly available and chosen formal source of help was from healthcare providers at the NGH. Caregivers revealed their trust in healthcare



professionals at the hospital and indicated NGH as their primary source for help-seeking in medical and caregiving advice. As majority of the participants held very limited knowledge of dementia and caregiving skills, as well as limited access to information updates, they relied on doctors and nurses at the NGH to provide medical care for their relatives. They communicated with the health professionals frequently and updated them immediately when a new symptom or concern started to show, such as incontinence. A few caregivers with larger social network, including healthcare professionals in other hospitals, also accessed those professionals for extra medical and caregiving advice. With the medical information support from the health professionals, caregivers felt more confident in providing daily care for the care recipients, as a spousal caregiver expressed: *“I am not sure if I know enough, but I think I have the basic information (from the doctor) to inform my daily caregiving.” (CG14, Female, 70).*

In addition to the formal healthcare services provided at the NGH, caregivers also considered other services, such as day time clinics and nursing home, as other sources for their need of medical care assistance for the care recipients. Older participants who had been taking care of care recipients for a long time were open-minded about seeking extra help from other services, such as a day care service. The demand for the day care services emerged from the challenging caregiving situation of long-term caregivers, especially among those who cared for relatives with severe dementia for more than three years. These caregivers reported their feeling of being trapped at home with the care recipients for years, as well as burnout from constant caregiving demands and multiple social roles. Most of the caregivers in this situation did not receive adequate family support in hands-on care activities, and as a result, they expected the formal support from the outside

services to reclaim a few hours every week for respite. Despite their expectation of extra services as a possible source for their caregiving, participants could not access them due to their unavailability in Vietnam.

Nursing home, surprisingly, was a desired option among many older caregivers who had been taking care of care recipients at an advanced stage of Alzheimer's Disease. Currently, all participants took care of care recipients at home, and they expected to provide home care for their loved ones as long as possible. Adult child caregivers did not prefer the option of a nursing home because they were concerned with social pressure and judgment targeting their filial obligation. Spousal caregiver, however, held very practical and realistic views of their future caregiving plan. Many of them considered and/or already did their own research on the availability of nursing home in their location as the last option when they might not be able to maintain their caregiving role. Like many other spousal caregivers in this study, this caregiver explicitly discussed her decision of a nursing home for her husband in the future:

*In the future, if there is a nursing home in my province, and I am too old and too weak to take care of him, I will send him there. I think a nursing home will be a good option at that time. I heard that the provincial authority is planning on a new nursing home. (CG11, Female, 56)*

Nursing home becoming a favored option for many spousal caregivers was likely associated with older caregivers' values of independence and autonomy. Most older caregivers did not want to "bother" their children to ask them for help with hands-on, direct care activities for the care recipients. They would rather to undertake all caregiving activities by themselves, or send the care recipients to a nursing home than requesting their children to take over the role of a primary caregiver. Spousal caregivers also emphasized the strong bonding between them and their spouses. They believed that only

they would provide the best care for their loved one and their children would not be able to provide a great care as they did. Using rational choice, they preferred a nursing home for their spouses in the future. In spite of the open mind and willingness of family caregivers to seek help from external services, including day clinics and nursing home, these services are rarely available in Vietnam. The Dementia Program at the NGH was the only option, as well as the primary formal source for family caregivers to seek help from.

***Informal sources.*** When formal sources were limited, family caregivers mostly sought help from informal sources. Participants reported diverse informal sources available in their social network, including family, neighbors, friends, hired maid, and religious/spiritual facilities. Among these sources, family which referred to both nuclear and extended family, was considered the primary source for help-seeking for different problems, such as medical advice and assistance with short-term, temporary tasks. For caregivers in the rural areas, they often lived in close proximity to their extended families. This residential distribution motivated their help-seeking within their family circle. Some caregivers shared that they just needed to make a phone call to some of their relatives, such as cousins, aunts, nieces, and nephews, and at least one of them would come for help immediately. A few caregivers also revealed that they received meaningful informational support from their relatives to enhance their caregiving. For example, a spousal caregiver reported feeling “relieved” because he received medical advice from his great support network of “*five doctors in the family, including brothers, sisters, and sisters-in-law.*” In addition, participants who lived in the rural areas with a strong sense

of community cohesion reported that they did not face any difficulty in asking for help from their neighbors in supervising their care recipients for a few hours.

Family caregivers were clear about the priority of sources to ask for help in needed situations. Family was always the first option for participants to ask for help. Only when this option was not available or too limited, caregivers would consider the second option of friends or neighbors. A spousal caregiver said: *“When I need to ask for help to take care of him, I will ask my children first. Always ask my children first, then my neighbors. When his illness gets worse and I feel worried, I called my children to go home and discuss the solutions.” (CG13, Female, 68).*

The option of asking for help from adult children and neighbors, however, was not available to many participants living in urban area. Instead, these participants assessed their available human and financial resources to make a decision of their help-seeking strategies. In-home maid became an alternative option to many older caregivers caring for their spouses with stable, adequate financial resources. Participants who were physically and socially ‘trapped’ in their caregiving role found the assistance of a hired maid helpful. A spousal caregiver was open about her difficulty in caregiving before hiring a maid: *“Two years ago, I merely went outside of the house. If I had to take him somewhere, I would hold his hand like this. If I did not do that, he would walk away when I looked down on an aisle in a store.” (CG14, Female, 70).* Despite having a maid, caregivers like her still undertook the primary caregiving role with long-hour hands-on care. The help of a maid allowed them to have decent amount of time for physical and mental break, as well as socialization. Some caregivers started having a few-day-vacation after many years staying home full-time with the care recipients. Depending on the

condition of the care recipient and the situation of the caregiver, the support of a hired maid became significantly important. An older caregiver who took care of his wife with severe cognitive impairment, extremely disruptive and violent behaviors, and high dependence in ADLs noted on his pressing need of hired maids when his children lived abroad:

*I usually request help from the maid when I really need her. But I am still the primary caregiver, as long as I am capable of caregiving. If my health decreases, I will need to hire two maids. Yes, two maids. I already plan that I will hire one more maid when my health does not allow me to take care of my wife directly. I will lead the two maids in caregiving. For example, I will tell them how to bathe her. Maids do not pay attention to caregiving duty like I do. I have to remind them to clean her underarms. Caregiving must be carried out very carefully. I will lead them. I will need two maids. I accept that I will have to spend much more money. Caregiving for someone with this disease is often expensive and required sacrifices. (CG18, Male, 77)*

Another common informal source from which Vietnamese family caregivers sought help was religious/spiritual facilities. While most participants self-declared as non-religious, they often revealed some specific spiritual beliefs. The practice of ancestor worship and the beliefs of Buddhist teaching, such as karma, cause and effect, and the importance of compassion were shared across all caregivers. Many of the participants visited Buddhist temples as a form of self-care. They considered Buddhist temples a temporary shelter of peace and quietness where they prayed for their families despite their self-identified non-religious status. A few caregivers held strong religious beliefs, particularly Buddhism, and applied Buddhist teaching to make sense and cope with their adverse situations. Religious and/or spiritual facilities then became a significant source for help-seeking for those caregivers.

*Yes, sometimes I visit a Buddhist temple. I cannot go often, but I go sometimes to practice chanting with others at the temple. Since I have had a housemaid, I try to go to the temple to chant every first or middle day of the lunar month to help*

*myself relieved. Chanting helps lessen the burden in my heart. First, I pray for his treatment to go well and for him to get better even just a little bit, like you have the support from both worlds. I think so. Second, I think my karma is heavy, praying and chanting would help lessen it. When I ask: “Why does it (dementia) happen to him, a very good man?” some may tell me: “It is not from this life only.” Not from this life only, karma comes from many previous lives. It accumulates even when we do not know. Now I have to pay it back for my karma. If I pay more in this life, I will pay less in the next lives. This belief pampers me. It helps me feel relieved a little bit. (CG14, Female, 70)*

Vietnamese family caregivers showed complex religious and spiritual beliefs in their caregiving. Indeed, Vietnamese people held multiple strands of religious and spiritual beliefs, such as Confucianism, Taoism, Buddhism, and Catholicism (Braun et al., 1996; Hinton et al., 2008; Liu et al., 2008; Meyer et al., 2015; M. D. Nguyen, 1985). When Vietnamese seek help for their mental health problems, they tend to draw these multiple strands of religious and spiritual beliefs rather than solely rely on a single designated religion. Results from the studies of Nguyen’s (2014, 2015) also show this pattern among caregivers of people with mental disorders, as in the proverb: “*Có bệnh thì vái tứ phương*” (*When in sickness, pray to every god*).

In summary, this study explores help-seeking perception and behaviors of Vietnamese family caregivers providing care for their relatives with dementia. Their help-seeking process emerged from the data as an iterative process of four stages: (1) Disease and caregiving experience; (2) Cognitive appraisal; (3) Action; and (4) Outcomes. Particularly, the complex culturally based belief system of caregivers shaped their perception and intention of help-seeking to meet the demanding requirements of caregiving duties. These perceptions and intentions directed them in their help-seeking strategies. The key values of independence, devotion to their family members, and self-sacrifice were upheld consistently among all family caregivers. These key values were

associated with their complex beliefs in familism, karma, and good deed sowing and reaping influenced by multiple religious and spiritual strands. Vietnamese family caregivers, therefore, tended to carry out most of the caregiving activities by themselves before considering asking for help. Help-seeking was delayed until caregivers assessed the situations as out of their capacity to deal with independently, such as hospitalization for medical emergency. In this situation, family was always the primary source to seek help from, besides the medical support from the formal health services. Long-term caregivers for care recipients at the advanced stage of dementia expressed more pressing need to seek help to reclaim time for their self-care and more open to the option of a nursing home. The option of a nursing home, however, rarely existed in the country.

## **DISCUSSION**

Help-seeking is acknowledged a leading concern among family caregivers to cope with increasing demands of dementia care. Primarily, health scholars approach help-seeking of family caregivers as a process (Cornally & McCarthy, 2011; Levkoff et al., 1999). Cornally and McCarthy (2011) present their concept of help-seeking behavior as *“a complex decision-making process instigated by a problem that challenges personal abilities.”* (p. 280). This process is characterized by three attributes, including (i) problem focused, (ii) intentional action, and (iii) interpersonal interaction. The definition of Cornally and McCarthy (2011) mostly focuses on seeking help from formal services for health problems of people with dementia, while it does not take into account of emotional needs of caregivers, as well as of religious influence on their help-seeking perceptions and behaviors. To Vietnamese family caregivers in this study, help-seeking was an iterative process grounded in their complex cultural beliefs which was influenced by

multiple religious and spiritual strands, such as Buddhism, Taoism, Confucianism, and Catholicism.

Most theoretical models approach help-seeking process in the stage fashion with an emphasis on cognitive appraisal (Folkman & Lazarus, 1984). The transactional model of stress and coping theory (Folkman & Lazarus, 1984) presents four consequential stages of help-seeking in the healthcare system, namely: (i) Stressors; (ii) Cognitive appraisal with primary and secondary appraisal; (iii) Coping strategies; and (iv) Adaptation outcomes. On the other hand, the help-seeking model adapted from Mechanic (1978) by Levkoff et al. (1999) consists of four stages: (i) Disease and symptom experience, (ii) Symptom appraisal, (iii) Decision to seek care, and (iv) Contact with care providers. The study of Levkoff et al. (1999) focuses on the role of religion and ethnicity in the help-seeking process of diverse caregivers. The help-seeking process of Vietnamese family caregivers who cared for their relatives with dementia in this study is consistent with the mentioned stage processes, as it consisted of four stages: (1) Disease and caregiving experience; (2) Cognitive appraisal, including primary and secondary cognitive appraisal; (3) Action; and (4) Outcomes.

This study extends the line of research on help-seeking processes by highlighting the stage of cognitive appraisal, which was significantly shaped by caregivers' cultural beliefs, such as devotion to family, self-sacrifice, as well as independence and autonomy. Self-sacrifice was found among Vietnamese immigrants who care for their relatives with dementia (Hinton, Tran, Tran, & Hinton, 2008). On the other hand, independence and autonomy are a highly favored value in the Western culture. Westerners, particularly older adults, therefore, share their fear of becoming dependent which is considered an



attribute of identity loss (Bell & Menec, 2013; Kathy Charmaz, 1983; Hooyman & Kiyak, 2010). Results in this study confirms these values and fear as a barrier to reach out for help in the context of Confucianism-based culture and Eastern tradition. This perspective is consistent with Vietnamese caregivers' high values of devotion to family and self-sacrifice, and likely reflects the influence of Western culture and thinking patterns on Vietnamese family caregivers in the changing sociocultural situation

Associated with the values of independence, autonomy, devotion to family, and self-sacrifice, Vietnamese family caregivers in the study sought help only when they considered the situations '*out-of-hand*,' or when they cannot handle caregiving duty themselves despite their efforts. '*Out-of-hand*' situations referred to the lack of knowledge and skills in dementia care of caregivers, or when caregivers needed short-term, temporary assistance for hands-on, direct care. The common problems which caregivers sought help for included information seeking for medical care decision-making, interpersonal communication, task sharing in hands-on care, caregiving emergency (e.g., hospitalization), and self-care. Vietnamese family caregivers sought help to reclaim time for self-care only when they reached their physical and psychological limits and often burned out. This was found quite often among long-term spousal caregivers of people with late dementia. Seeking help to find time for self-care was also found among spousal caregivers in Canada (Furlong & Wuest, 2008). Furlong and Wuest (2008) indicate that Canadian spousal caregivers suppressed their need of self-care while providing care for their loved ones with Alzheimer's Disease till the point they realized its serious effect on their health and decided to reclaim self-care.

Vietnamese family caregivers in this study sought help from multiple sources, including both formal and informal sources, but family remained the primary and most important source for help-seeking in dementia care. This result is similar to what were reported in existing studies with both Vietnamese people and Vietnamese immigrants (Braun & Browne, 1998; Braun et al., 1996; Liu et al., 2008; Meyer et al., 2015; B. N. Nguyen et al., 2018; Truong, 2015; Yeo et al., 2002). To Vietnamese family caregivers, familism played a pivotal role in shaping their help-seeking strategies. Family harmony and cohesion were not only acknowledged as key values, but also pride and social standards to direct caregivers' help-seeking behaviors. Vietnamese caregivers expected to receive voluntary and substantial family support. The frequency and quality of family support, therefore, could serve as either a protective factor or a risk for their mental health (Miyawaki, 2015).

Results in this study also emphasize the preference of help-seeking in the formal system among Vietnamese family caregivers to meet caregiving demands for their loved ones with dementia. Different from existing studies on Vietnamese immigrants (Braun & Browne, 1998; Braun et al., 1996; Liu et al., 2008; Meyer et al., 2015; Truong, 2015; Yeo et al., 2002) and Vietnamese people living with mental illness (Nguyen, 2014, 2015), participants in this study placed their trust in and favored formal sources, particularly the NGH, as a key source to seek help while only considered religious/spiritual facilities secondary or minor sources. Older spousal caregivers were also much more open to the option of nursing home, which contrast with results of the former studies (Meyer et al., 2015; Truong, 2015). Given the fact that all participants in this study were recruited from the NGH, they were more likely to open to seek help from the formal system than

caregivers who were not associated with the hospital. The study results may reflect the modernized and Westernized views of a specific group of Vietnamese family caregivers in the interwoven culture of different traditions and trends of thoughts in Vietnam. This result, however, needs to interpret with caution.

## **LIMITATIONS**

This study brings new and unique perspectives of help-seeking perceptions, behaviors, and process of Vietnamese family caregivers in dementia care. This study, however, has its limitations. First, the study results were based on a relatively small sample size of participants with homogeneous characteristics. All 20 family caregivers of people with dementia were recruited from the same Dementia Program at the NGH. As the caregivers were already receiving formal support from the NGH, their help-seeking perceptions and strategies are most likely very different from other caregivers in the community who did not seek help from the hospital. Thus, these study results are limited in their generalizability to those Vietnamese caregivers whose relatives have been diagnosed and receive medical care through the hospital. However, this sample size and characteristics are considered sufficient and reasonable for theoretical saturation in an exploratory study (Guest et al., 2006).

Second, language translation between Vietnamese and English may challenge meaning transfer in data analysis. All interviews were conducted, verbatim transcribed, and analyzed in Vietnamese language. Result synthesis, however, was conducted in English. It is challenging to convey some terms and proverbs reflecting Vietnamese culture and traditional thoughts into English. Data analysis on the original Vietnamese transcripts, however, increases the accuracy and sensitivity of meaning transfer. The

cross-checking of the two Vietnamese American committee members also helps protect the validity of the data analysis and synthesis.

## **CONCLUSION AND IMPLICATIONS**

This study contributes to the literature the current perspectives of help-seeking perception, behaviors, and process of family caregivers living in Northern Vietnam. The results highlight cultural values of independence, autonomy, devotion to family, and self-sacrifice which shaped their help-seeking patterns. Along with this perception, participants also showed their patterns of help-seeking in both formal and informal sources. This calls for further studies to expand the examination of help-seeking perception and behaviors regarding dementia care among Vietnamese family caregivers. To be more specific, further studies with larger sample sizes, diverse participants with heterogeneous characteristics from participants in this study, and in different settings would supplement the understanding of help-seeking of caregivers in the Vietnamese context.

Furthermore, the study results advocate for the needs of service development targeting Vietnamese family caregivers for older adults with dementia with respect to the changing context in Vietnam. A recent report of UNFPA (2011) raises a concern about the changing in culture and lifestyle of modern Vietnamese people. According to this report, living arrangements and the social supports of Vietnamese older adults are in flux. Under the rising migration trend, adult children tend to migrate to urbanized and industrialized areas for job opportunities, leaving their older parents and grandparents in the rural areas. This situation likely changes the traditional support system of older adults, including those with dementia, in their healthcare practice and help-seeking. As

reported in the study results, family caregivers' perception and beliefs of independence, autonomy, devotion to family, and self-sacrifice rooted in their culture and tradition possibly hindered their help-seeking behaviors. Hence, culturally competent intervention and services for family caregivers are much needed, given the fact that formal services for family caregivers are almost non-existent in Vietnam (Truong, 2015). For example, providing professional social work services in the setting of the hospital, such as the NGH, would likely ease the reluctance to seek help and support the decision-making process of family caregivers to access the feasible sources for their care-related problems, including self-care.

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Table 3.1

Characteristics of caregivers and care recipients

Characteristics	Caregiver participant (N = 20)		Care recipients (N = 19)	
	n	Mean (Range)	n	Mean (Range)
Gender				
Male	7		11	
Female	13		8	
Geographic area of residence				
Rural area	7			
Urban area	13			
Educational level				
Primary school	1		5	
Secondary school	4		5	
High school or Vocational school	5		3	
College or higher	10		6	
Job				
Retired	13			
Farmer	3			
Public officer	3			
House-maid	1			
Marital status				
Married	18			
Single/Divorced/Separated	1			
Widowed	1			
Relationship with CR				
Spouse	13			
Daughter	4			
Daughter-in-law	1			
Son	1			
Son-in-law	1			
Number of people in the household		4 (2 – 10)		
Age		61 (34-86)		73 (57 - 88)
Hours of caregiving per day		7 (3-8)		
Estimated years of dementia exposure				5 (1 – 20)
Estimated months of treatment in NGH				30 (1 – 96)

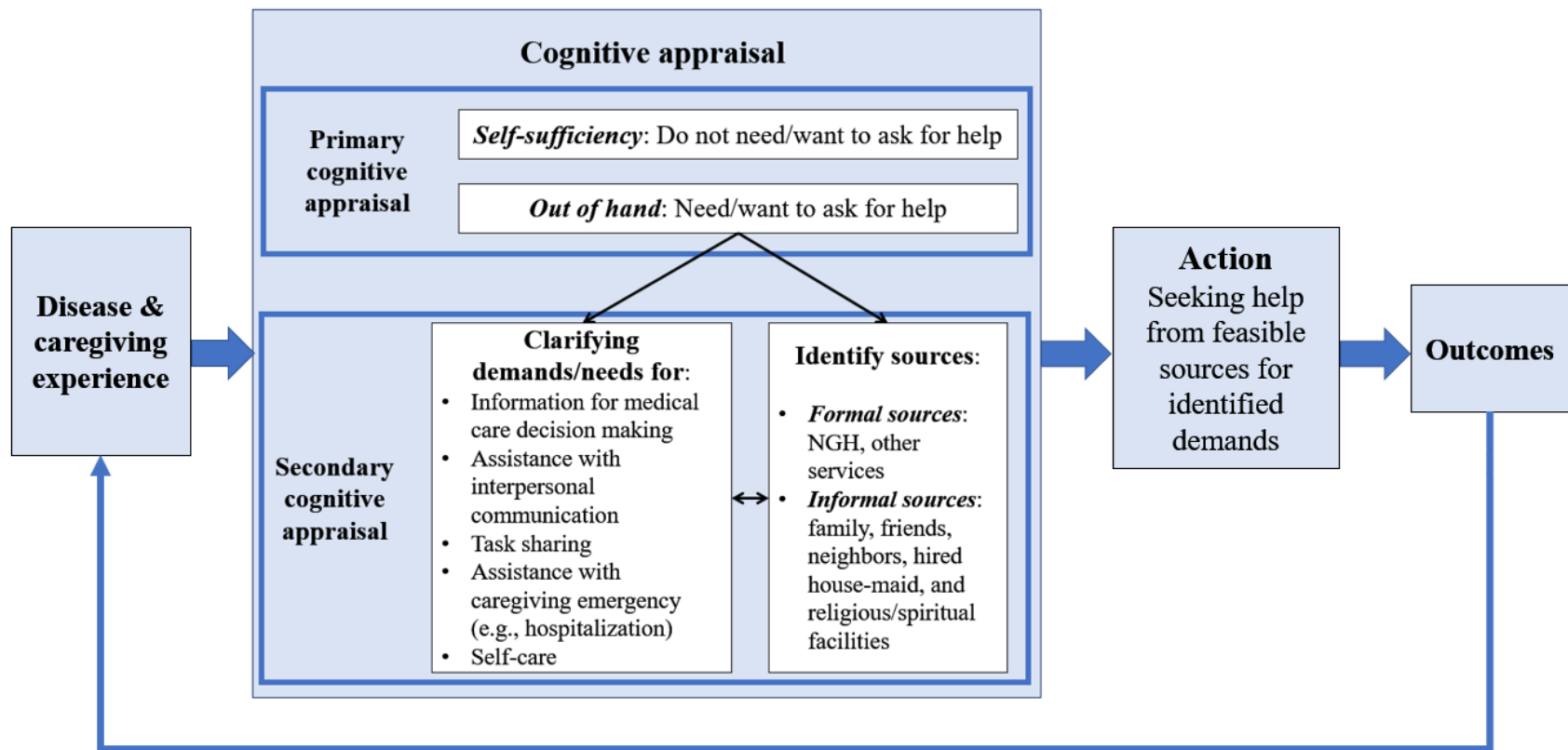


Figure 3.1 Help-seeking process of Vietnamese family caregivers in dementia care

## CHAPTER 4

### PAPER 3: “WHAT WILL COME WILL COME”: THE MULTIPLE PATHS TOWARD VIETNAMESE FAMILY CAREGIVERS’ ACCEPTANCE OF THEIR CAREGIVING ROLE IN DEMENTIA CARE<sup>3</sup>

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<sup>3</sup> Nguyen, T. “What will come will come”: The multiple paths toward vietnamese family caregivers’ acceptance of their caregiving role in dementia care. To be submitted to *Qualitative Health Research*.

## **Abstract**

This paper explores the psychological process through which Vietnamese family caregivers adjust to their role as primary caregivers for their relatives with dementia. The study adopted a constructivist grounded theory approach to collect data with 30 face-to-face, semi-structured interviews with 20 self-identified primary caregivers of older adults with dementia in Vietnam. The core adjustment process, consisting of four stages (*Experience, Acknowledgement, Experiment, and Acceptance; EAEA*) to caregiving role emerged from the data. The EAEA process highlighted the importance of self-concept, self-identity, and self-acceptance of caregivers, and referred to their adaptation to the development of ‘*the self*’ in caregiving. The core EAEA process was in the transactional relationship with caregiver personal factors (demographic and relationship characteristics with care recipients; personal beliefs and commitments in caregiving; and personal history of caregiving and coping with past adversity) and structural factors (cultural values and norms; social support; and social pressure). The two-level factors interacted with each other to impact the psychological adjustment process of Vietnamese family caregivers.

## **Keywords**

Dementia; Alzheimer’s Disease; Vietnamese family caregivers; adjustment process; constructivist grounded theory

## INTRODUCTION

Providing care for a relative with chronic disease is a challenging job and requires family caregivers to adjust to this role. Adjustment process refers to the process of *“making sense of, coming to terms with, and adapting to changes in functioning, typically loss of function, following the onset of an injury or illness”* of self or family members (Ownsworth & Gracey, 2010, p.1). The adjustment process is a coping process in which family caregivers go through to adapt to different aspects of caregiving, such as the acceptance of the caregiver role, care duties, changing symptoms of the chronic condition of the loved one, changes in family dynamics, and self-care for caregivers themselves. Dementia is one of the hardest chronic condition for family caregivers to deal with (Baltes, 1996).

In Vietnam, dementia was reported as one of the leading health burdens to older adults (Bang et al., 2017; Truong, 2015). Meanwhile, the older adult population, consisting of those who aged 60 and above, has increased rapidly and significantly in the country over the decades (Tatarski, 2016; United Nation Population Fund [UNFPA] Vietnam, 2010, 2011). In 2014, there were approximately 9.5 million older adults, accounting for 10.45% of the total Vietnamese population. The Vietnam’s General Statistics Office (2016) predicted that this demographic group will take up to 30.8% of the total population in 2050 (General Statistics Office [GSO] & UNFPA, 2016; HelpAge Global Network, n.d.). Health and caregiving burdens associated with aging have recently been acknowledged as one of the greatest concerns to the Vietnamese government (Tatarski, 2016; UNFPA, 2010, 2011).



In Vietnamese society, dementia caregiving is primarily considered a family responsible (B. N. Nguyen et al., 2013; Truong, 2015). This caregiving practice deeply reflects the Confucianism-based culture, which highly values filial piety and familism (Dam, Tran, Duong, Khuong, & Nguyen, 2009; Truong, 2015). The cultural foundation not only shapes the social norms and expectation towards family members, but also influences the laws. For example, the Law on the Elderly explicitly declares the responsibility of caregiving for older adults, particularly those with sickness, to their children and grandchildren (Vietnam National Assembly, 2010). Within this context, Vietnamese family caregivers carry out intensive care duties without much effort for help-seeking outside of their families. Meanwhile, recent studies also find very limited supports in the formal system for families of older adults with dementia (B. N. Nguyen et al., 2013; Truong, 2015).

Given this typical caregiving situation, Vietnamese family caregivers face multiple challenges to their adjustment to the caregiving role. Scholars discuss multiple caregiving burdens among Vietnamese family caregivers in their studies (B. N. Nguyen et al., 2018; T. B. Nguyen et al., 2018; Truong, 2015). Physical health problems, such as sleep disturbance and fatigue were found commonly among caregivers. They also reported psychological distress, such as anxiety, as well as time constraint, and financial hardship (T. B. Nguyen et al., 2018). Family caregivers were more likely to experience higher caregiving burden when their relatives' dementia symptoms progressed (B. N. Nguyen et al., 2013). High perceived burdens, along with the lack of confidence in caregiving management, negatively impact quality of life of Vietnamese family caregivers (Truong, 2015). Despite these challenges, scholars know very little about how

Vietnamese family caregivers adjust to their caregiving role in their context. Therefore, this study aims to explore the psychological process through which Vietnamese family caregivers adjust to their roles as primary caregivers for older adults with dementia.

In the adjustment process to the caregiving role, coping plays the role of a central concept. Coping refers to efforts, strategies, and processes in which a person attempts to manage a stressful person-environment transaction with a consideration of available resources (Folkman & Lazarus, 1984; Folkman et al., 1986; Hinrichsen & Ramirez, 1992; Lazarus, 1993). Existing research investigates the adjustment of family caregivers to their caregiving role from the aspects of coping styles and processes (Aranda & Knight, 1997; Folkman, Lazarus, Gruen, & DeLongis, 1986; Gilhooly et al., 2016; Hawken, Turner-Cobb, & Barnett, 2018; Knight & Sayegh, 2010; Kramer, 1993; Lazarus, 1993; Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990). As a style, coping refers to its two major functions, including solving problems associated with distress (problem-focused coping), and regulating emotions emerging from the person-environment transaction (emotion-focused coping; Folkman & Lazarus, 1984; Folkman et al., 1986; Lazarus, 1993). Emotion-focused coping may be either avoiding or accepting the situation, minimizing or exaggerating the problem, or seeking positive or negative meanings of the same event. Problem-focused coping refers to problem identifying, solution planning, help-seeking, decision making, and acting (Cooper, Katona, Orrell, & Livingston, 2008; Gilhooly et al., 2016; Lazarus, 1993). In addition to emotion-focused and problem-focused coping, Kramer (1993) in his study on coping among dementia caregivers, presents another style of coping; relationship-focused coping. Relationship-focused coping is either positive (empathy with the patient and enhance the bond between

caregiver and care recipient) or negative (blame or be distant to the patient, Kramer, 1993).

In addition to styles, coping refers to stage-processes. One of the most popular theories which approach coping as a stage-process is the stress and coping theory (Folkman & Lazarus, 1984). Scholars have investigated adjustment process of family caregivers in dementia care using this theory at least over the past three decades. This stress and coping model proposed by Folkman and Lazarus (1984) consists of the core coping process and influencing factors on the core coping process. The core coping process refers to a sequence of (1) stressors; (2) cognitive appraisal; (3) coping strategies; and (4) adaptation outcomes. The influencing factors include both personal factors (caregiver demographics, relationship with care recipients, beliefs, and commitments) and structural factors (ethnicity, cultural values, and social supports; Folkman & Lazarus, 1984). This model has been widely applied to investigate family caregivers from different races and ethnicities, such as Latino and Taiwanese, in different contexts (for example, Haley, Levine, Lane, & Bartolucci, 1987; Montoro-Rodriguez & Gallagher-Thompson, 2009; Pinquart & Sörensen, 2005; Stolley, Buckwalter, & Koenig, 1999). These studies mostly focus on examining the relationship between specific variables, such as caregivers' demographic characteristics and their health outcomes. Their results all provide evidences to support the stress and coping model (Folkman & Lazarus, 1984). By far, only the study of Truong (2015) adopts this model to test the association between Vietnamese caregivers' perceived burdens and their quality of life. Although his study results support the tested relationship, this study did not investigate the psychological adjustment process of caregivers.

Along with studies testing the stress and coping model of Folkman and Lazarus (1984), the literature reveals numerous studies exploring the adjustment process of family caregivers who take care of relatives with dementia inductively using qualitative methods, such as grounded theory or phenomenological inquiry (for example, Butcher, Holkup, & Buckwalter, 2001; Silverberg, 2006; Willoughby & Keating, 1991 as cited in Butcher et al., 2001). These studies all reported family caregivers' coping in the stage-processes. For example, Silverberg (2006) reports three stages of grief management among family caregivers, including: (i) acknowledging loss and grief; (ii) assessing caregiver grieving style and denial; and (3) Assisting through taking respite and clinical strategies. Although the reported stage-processes in the existing qualitative studies label each stage differently, e.g., in the three-stage grief management of Silverberg (2006), they are consistent with the stress and coping model of Folkman and Lazarus (1984). None of these studies include Vietnamese family caregivers as their informants.

Overall, a substantial body of the literature has examined the coping processes of family caregivers in dementia care in diverse contexts. However, further studies on family caregivers' adjustment processes are still much needed for several reasons. First, a majority of the previous studies focus on coping outcomes of caregivers, such as their health outcomes in Taiwanese caregivers (Huang, Musil, Zauszniewski, & Wykle, 2006) and quality of life of Vietnamese caregivers (Truong, 2015). These studies did not look at the process of coping with its cognitive and behavioral attributes. Lazarus (1993) argues that coping, including cognitive and behavioral responses, should be assessed separately from its outcomes. Second, studying coping of caregivers must be considered in their context and time, as well as the specific sources of stress. Coping changes over time in an

accordance with the change in care demands and distress. Gilhooly et al. (2016), after conducting a meta-review of 46 systematic reviews of caregiver coping with dementia care, synthesize that existing studies address coping strategies for caregiving distress very broadly and generally without any specific concentration on any sources of stress. That means there is a lack of “*specific remedies for specific sources of stress*” of family caregivers (Gilhooly et al., 2016). Third, in order to understand the coping process of family caregivers, researchers need to explore both their perceptions and actions in the transaction between caregivers’ internal processes, such as cognitive appraisal, and their environments. Taken together, it is important to conduct a study to explore the psychological adjustment process of Vietnamese family caregivers to their caregiving role in their current sociocultural context. This demand becomes more critical given the situation that Vietnamese family caregivers face a variety sources of stress rooted in their socioeconomic and cultural context of a developing country (Truong, 2015). In addition, their coping is significantly impacted by their complex beliefs, including religious and spiritual beliefs (Braun & Browne, 1998; Braun et al., 1996; Levkoff, Levy, & Weitzman, 1999; Liu, Hinton, Tran, Hinton, & Barker, 2008; Meyer et al., 2015; Truong, 2015; Yeo, Tran, Hikoyeda, & Hinton, 2002).

This study addresses this knowledge gap by exploring the psychological adjustment process of Vietnamese family caregivers to their caregiving role for their loved ones with dementia. Appearing to be the third of the trilogy, this paper reports part of the results from a larger constructivist grounded theory study on caregiving experiences of Vietnamese family caregivers in dementia care. The two other papers contribute to understanding in Vietnamese family caregivers’ perceptions of dementia,

caregiving, and associated factors with their caregiving, as well as their help-seeking perceptions and behavioral patterns in dementia care. This paper not only connects to the two previous ones, but also synthesizes the results of the larger study as a whole.

## **METHOD**

### **Research design**

This paper draws on a larger study using the constructivist grounded theory approach (Charmaz, 1990, 1997, 2014). This approach, which is built upon the symbolic interactionist perspective, is particularly appropriate to examine experiences of Vietnamese family caregivers for the following reasons. First, constructivist grounded theory provides a powerful approach for researchers to understand lived experiences of participants from their perspectives (Charmaz, 1990, 2014). Second, constructivist grounded theory takes into account context and culture of participants, which is critical in studies with diverse groups, such as Vietnamese family caregivers (Carroll et al., 2007; Liu et al., 2014, 2015; McCalman et al., 2013; Mendez-Luck et al., 2016; Ononeze et al., 2009; Waterworth et al., 2016).

Adopting the constructivist grounded theory approach (Charmaz, 1990, 2014), the study was conducted iteratively (*Figure 4.1*). The preliminary literature review contributed to refine the research aims, research questions, and conceptual framework of this study. Theoretical sampling and constant comparative methods were critically applied in this study. The data collection and analysis were conducted iteratively for theory integration (Charmaz, 1990, 2014; Ng & Hase, 2008).

## **Ethical consideration**

Before the phase of data collection, the research protocol in both English and Vietnamese language was approved by the University of South Carolina (USC) Institutional Review Board (IRB) and the National Geriatric Hospital (NGH) where participants were recruited. At the beginning of each interview, the researcher handed each participant an informed consent written in Vietnamese and explained about the study procedure. The researcher emphasized participants' right to withdraw from the study at any time of their wish and their confidentiality protection. The researcher audited all transcripts to remove identifiable information of participants and assigned identification number for each transcript. Only the researcher could access to data securely stored in a computer with a password.

## **Sample**

### **Setting**

The participant recruitment was taken place in the National Geriatric Hospital (NGH) in Hanoi, Vietnam. The NGH is a public hospital at the national level in the healthcare service system of the Ministry of Health (MOH). The MOH runs a four-tier healthcare service system, consisting of health clinics and hospitals throughout the precinct-, district-, province-, and nation-levels across the country. Not all provincial hospitals operate geriatric services. Only 28 out of the total of 63 provincial hospital provide specialized health services for older adults through their geriatric departments (H. Nguyen, 2016). At the national level, the NGH was known for the only specialized geriatric care unit in the country with the Dementia Program running under the Department of Neuropsychiatry and Alzheimer's Disease. This program was funded by

the government with the purpose of providing high quality and affordable medical treatment for older adults clinically diagnosed with dementia through their health insurance, which covers from a half to the total of their medical bills. NGH was one of a few healthcare units in Vietnam using Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM IV TR; American Psychiatric Association [APA], 2000) to diagnose dementia. The health professionals, including four psychiatrists, 15 nurses, and a nurse assistant, provide medical treatment with prescribed medicines, such as Aricept and Razadyne (Galantamine), for dementia symptoms. On the yearly basis, they provide medical treatment to approximately 130 out-patients with dementia (B. Nguyen, personal communication, March 19, 2017).

### **Participant recruitment**

Participants were recruited using purposive sampling with the support and supervision of healthcare professionals, including doctors and nurses, from the NGH's Department of Neuropsychiatry and Alzheimer's Disease where operated the Dementia Program. Purposive sampling (Charmaz, 2014; Guest et al., 2006) was used to recruit participants for the study. Healthcare professionals in the Dementia Program assisted the two-step participant recruitment process. In step 1, based on the list of patients clinically diagnosed with dementia in the Dementia Program, psychiatrists and nurses contacted the designated family caregivers of those patients to explain about the study and distributed the recruitment flyers. Family caregivers who were interested in participating in the study agreed for the psychiatrists and nurses to give the researcher their phone numbers. In step 2, the researcher made phone calls to interested caregivers to explain further about the study protocol and screen their eligibility for the study. The inclusion criteria were used



to select caregivers who: (1) were at least 18 or older; (2) self-identified as primary family caregivers who have provided direct, hands-on, and substantial day-to-day care (minimum 20 hours/week) for a family member clinically diagnosed with dementia; (3) had taken care of the relatives with dementia for at least one year consecutively; and (4) had no self-declared cognitive disability and can communicate in Vietnamese. The total of 20 caregivers who met the inclusion criteria were invited to set up time and location for the interviews.

### **Data collection**

Prior to data collection with eligible family caregivers, a pilot study was conducted with two dementia caregivers in order to test the feasibility and cultural appropriateness of the interview protocol. Using personal network and word of mouth, the researcher recruited two participants who self-identified as family caregivers of relatives with memory impairment. The researcher reviewed the audio records, field notes, and memos of the pilot interviews to revise the interview protocol. These documents were not included in the data analysis of the study.

After the pilot study, the researcher started collecting and analyzing data iteratively following the principle of theoretical sampling (Charmaz, 1983, 2014; Corbin & Strauss, 2014; Creswell et al., 2007; Creswell, 2012). When the first 10 interviews were completed, the researcher started preliminary data analysis by reviewing interview digital records and transcripts, field notes, and reflective memos. Analytic memos were also conducted to develop initial codes and themes emerging from exiting data. This process helped refine recruitment strategy of new participants, and interview questions in follow-up interviews. A total of 20 more interviews, including 10 follow-up interviews,

were conducted. This theoretical sampling ceased after the 30<sup>th</sup> interview when the researcher found theoretical saturation, i.e., no new findings emerged from the data (Charmaz, 2014; Corbin & Strauss, 2014; Creswell et al., 2007; Creswell, 2012; Guest et al., 2006; Ng & Hase, 2008; Strauss & Corbin, 1997).

Overall, the researcher conducted 30 face-to-face, semi-structured interviews with 20 eligible participants. The average time of an interview was 58 minutes, varied from 30 to 97 minutes. Interviews took place at participants' homes or the hospital upon their preferences. Participants received \$15 incentive for each complete interview.

As the study aimed to explore participants' perspectives grounded in their sociocultural context, the interviews were conducted inductively. At the first interview with each participant, the researcher started with a broad question: "*Tell me about your experience of living with/caring for your relative.*" Depending on the response of each participant and the flow of the conversation, deeper and more detail-oriented questions were probed (*Appendix A*).

All interviews were approved to record digitally and then transcribed verbatim in the original language of Vietnamese by a professional Vietnamese transcriber. The researcher audited approximately 411 pages of interviews transcripts to remove identifiable information of participants from the transcripts. Their demographic information was recorded in a Microsoft Excel Sheet for the purpose of data analysis. Field notes, including observation notes, reflective and analytic memos were used to supplement and triangulate data for analysis and synthesis.

## **Data management and analysis**

The data analysis using the qualitative data analysis program MaxQDA12 was conducted iteratively with data collection. Audited interview transcripts and memos were uploaded, managed, and coded with MaxQDA12. Data analysis conducted on the original Vietnamese-language-transcripts helps protect the cultural and linguistic authenticity in meaning interpretation (Haidar, 2013; Shibusawa & Lukens, 2004). This also contributes to improve the internal validity of the results. Besides, validity checking regarding language translation in quotes and result synthesis were conducted by two dissertation committee members, who have profound understanding of Vietnamese culture and language. The validity checking reduces the validity threats associated with language translation and meaning interpretation.

Interview transcripts were analyzed using the three-phase coding procedure suggested by Charmaz (2014). This coding procedure consists of initial coding, focused coding, and theoretical coding (Charmaz, 2014). In the initial coding phase, the researcher conducted line-by-line coding to construct initial categories, followed by the second phase of focused coding which the most significant and frequent codes and categories were examined throughout all transcripts. In the last phase of coding, theoretical coding, the researcher selected core categories and subcategories to develop an integrative theory to explain the adjustment process of Vietnamese family caregivers to their caregiving roles in dementia care. Within the scope of this paper, the core categories included: (1) the core psychological process through which Vietnamese family caregivers adjust to their caregiving role; (2) personal factors that influence the core adjustment process; and (3) structural factors that influence the core adjustment process.

Theoretical sorting, constant comparative strategies, and diagramming were also adopted to support the theory integration (Charmaz, 1990, 2014; Ng & Hase, 2008). Results reported in the two previous papers, including caregivers' perceptions of dementia, caregiving, and facilitators and inhibitors to caregiving, as well as help-seeking perceptions and patterns, were used to support the result of the adjustment process in this paper.

## **RESULTS**

### **Participant characteristics**

The study was conducted with the total of 20 participants from different backgrounds (*Table 4.1*). The average age of 20 participants, including 13 women and seven men, was 61, ranged from 34 to 86. Most of the participants were married ( $n = 18$ ), retired ( $n = 13$ ), taking care of their spouses ( $n = 13$ ), and living in urban areas ( $n = 13$ ). A half of the participants held a college degree or higher. They all self-identified as the primary family caregiver of the care recipient and self-estimated their average time spending on caregiving every day was seven hours, ranged from three to eight hours. Particularly, two out of 20 participants were taking care of the same care recipient. They both defined themselves primary caregivers but with different scopes of care duties. The care recipient's wife focused on providing hands-on, direct care, while his son-in-law was responsible for medication management and treatment decision-making.

The 20 participants were taking care of 19 care recipient, who were all clinically diagnosed with Alzheimer's Disease and enrolled in the Dementia Program at the NGH for government-funded medical treatment. The average age of 11 male and eight female care recipients was 73, ranged from 57 to 88. They had shown dementia symptoms for

averagely five years (ranged from one to 20 years) and enrolled in the Dementia Program for averagely 30 months (ranged from one to 96 months). Only six of the care recipients held a college degree while the rest of them held either a primary (n = 5), secondary (n = 5), or high school diploma (n = 3) as their highest educational level.

### **The ‘*Experience, Acknowledgement, Experiment, and Acceptance (EAEA)*’ process**

The adjustment process of Vietnamese family caregivers to their caregiving role for their loved ones with dementia consists of four iterative stages, consisting of (1) *Experience*; (2) *Acknowledgement*; (3) *Experiment*; and (4) *Acceptance (EAEA)*. This EAEA process emerged from the data of the 30 interviews with 20 Vietnamese family caregivers, and reflects the most salient adjustment process across all caregivers in the study. Before explaining each stage of the EAEA process, it is important to emphasize its key characteristics. First, not all family caregivers reached the last stage of acceptance. For example, a female caregiver revealed her feeling of ‘*being trapped*’ in her caregiving role for her mother-in-law. She had taken care of her mother-in-law for more than 20 years, and has been in charge of her dementia caregiving for the past three years, but she could not accept her role and situation of a primary caregiver.

Second, this process is not a linear process with a clear cut between each stage. Each caregiver had different life experiences depending on their backgrounds and contexts. Family caregivers went through the adjustment process with different paces regarding these stages. Some caregivers experienced multiple stages at the same time and progressed to their acceptance within a short period of time, whilst some others stayed in one stage for years before transiting to the next one. Another female caregiver showed a

significant transition across stages toward acceptance over the three interviews which were conducted within six months.

Third, the EAEA process through which Vietnamese family caregiver went through to adjust to their caregiving role for their loved one with dementia was significantly shaped by their personal and structural factors. Caregiver personal factors refer to their demographic and relationship characteristics with care recipients; personal beliefs and commitments in caregiving; and personal history of caregiving and coping with past adversity. The structural factors refer to cultural values and norms; social support; and social pressure. The personal and structural factors interact with each other to impact their psychological adjustment process. The two-level factors are discussed after the four-stage EAEA process.

In short, the EAEA model does not aim to unify diverse experiences of Vietnamese family caregivers from different backgrounds into an over-simplified, fixed stage process. The EAEA model, instead, aims to provide a framework to understand the core essential experiences of Vietnamese family caregivers in a flexible, iterative stage fashion. The adjustment process may take a lifetime to some caregivers. A few caregivers went through this four-stage process multiple times. Acceptance is not only an ultimate goal of the adjustment, but also a learning process evolving over times. As caregiving situation constantly changed, family caregivers continued to learn and develop resilience and skill set to adapt.

### **Experience (E)**

The journey to adjust to caregiving role in dementia care started when caregivers were exposed to early signs of dementia, followed by their role-taking, as well as their

role transition between before and after the diagnosis of their loved ones. Their experiences of the illness and caregiving also included their management of hands-on caregiving activities and symptom changes during their hands-on care.

***Being exposed to the onset of dementia.*** Even though most caregivers did not refer their relatives' symptoms to dementia at the early stage, they noticed the unusual signs or changes in their relatives' cognitive abilities, emotions, and behaviors. Most caregivers recalled exactly when their relatives did not act like "*they used to before*" and began to act like "*a new different person.*" For example, a spousal caregiver marked the event when her husband did not help her carry their luggage at the airport as the starting point of their journey with dementia. As other caregivers, she paid more attention to her husband but did not associate his symptoms with dementia until learning about his diagnosis at the NGH a few years later. Depending on the cases, it took from a few months to a few years for family caregivers to start seeking medical assessment for their relatives' symptoms at the NGH. Before the clinical diagnosis, most caregivers lived with doubts, uncertainty, worries, and assumptions of their relatives' conditions. The common assumptions were '*being confused*' as a consequence of the aging process, brain damages, physical injuries, or psychological distress.

***Taking on the role.*** Most of the caregivers approached their caregiving role in the illness situation voluntarily and willingly to fulfill their social responsibility and obligation associated with their position and role in the family, such as a spouse or an adult child. Being a spouse or the oldest child/child-in-law means that their caregiving role for the relative with dementia is taken for granted. Fitting the social norm in Vietnam, each family caregiver in this study was either a spouse or the oldest child/child-

in-law in the family of the person with dementia. A daughter-caregiver commented: “*My siblings are busy, so I take the role (of primary caregiver). My grandchildren are too young and my children have to work, not like they go out to have fun. So it is not a problem, I just do it (take care of her mother with dementia).*” (CG02, Female, 53). Their voluntary attitudes toward their primary caregiving role were associated with their culturally based values, such as ‘*responsibility/obligation*’ (trách nhiệm/nghĩa vụ), ‘*filial piety*’ (báo hiếu) among adult children caregivers, or ‘*affection and gratitude*’ (tình nghĩa) among spousal caregivers. Regardless of caregivers’ specific positions in the family as a child or a spouse, they all upheld the values and principle of familism. Putting family ahead of their individual interests and sacrificing for others in the family helped ease the transition of the caregiving role. Many caregivers explained that they had more time and caregiving experience than other members in the family, therefore, they initiated their role-taking to lessen the caregiving burden for others. Besides, there was no clear cut in the caregiving role transition between before and after the diagnosis of dementia in cases of caregivers for relative with early dementia, who showed less severe symptoms. Most caregivers had already lived with and taken care of the people with dementia before the diagnosis. After learning about the diagnosis, these caregivers described their caregiving routine as “*just being the same,*” which eased their role transition.

Family caregivers’ attitudes and emotions toward their role-taking, however, varied depending on the level of social support received from their family network. Some long-term caregivers reported their feeling of ‘*being trapped*’ in their role and expressed their dissatisfaction and frustration from not receiving social support from other family members in caregiving for a relative with severe, advanced dementia. A daughter-in-law



noted: “*Taking care of someone like this (having dementia) is exhausting. No one wants to do it. I am the only daughter-in-law then I have no choice.*” (CG16, Female, 59). The attitude associated with the role-taking of each primary caregiver reflected their family cohesion, which refers to the emotional bonding and connectedness among family members (Olson, 1999). The caregivers who described their role-taking and maintenance ‘*unwanted*’ also reported low cohesion in their families.

***Managing hands-on care and symptom changes.*** After learning about the diagnosis of dementia, caregivers who already lived with the care recipients maintained their caregiving routine with additional and adaptive strategies to support their relatives. Caregivers focused on two key tasks, including medication management and activities of daily living (ADLs) care. Along with the prescribed medicines from the NGH, such as Aricept and Razadyne (Galantamine), most caregivers bought care recipients supplements for memory loss, for example, ginkgo biloba, and multi-vitamins within their budget. Even caregivers with financial hardship still saved their money to purchase extra supplements for memory loss as they shared that they wanted to try “*everything that might help even just a little bit.*” The care recipients were at different stages of dementia and showed different levels of cognitive impairment, disruptive behaviors, and dependence in ADLs. Those who were at the advanced stages of dementia required tremendous amount of time and effort for hands-on, direct care. Depending on the condition of the care recipient, each caregiver developed different skills to handle hands-on care that fitted the specific stages of their relatives. Caregivers for their relatives with late dementia often described their daily caregiving activities with intensive ADLs care, from feeding, bathing, shaving, brushing teeth, and cutting finger nails for the care

recipients, and even scrubbing them with soap when they put the toilet waste on their body. A spousal caregiver summarized: “*I take care of him from the smallest things.*” Hands-on caregiving in these cases was often challenging when the care recipients did not collaborate with and violently attacked the caregivers.

As dementia progressed over time, family caregivers also experienced multiple changes in their loved ones’ symptoms. Their hands-on caregiving strategies also changed to adapt to the new symptoms and caregiving demands. A very few family caregivers reported positive improvement in their relatives’ symptoms, such as sleeping better, reducing spitting and violent behaviors, as a result of the medical treatment at the NGH. Under the effect of described medication and guided care suggested by the NGH’s professionals, some caregivers positively reported that their relatives were able to better perform cognitive functions and interact with others. To those caregivers, they expressed their relief and reduced their workload related to caregiving. On the other hand, long-term caregivers of those who had advanced dementia experienced significant health decline and more severe cognitive and behavioral symptoms of dementia in their loved ones over years. In order to adapt to symptoms changes in their loved ones, caregivers had to spend more time and effort in supervising and taking care of their relatives, particularly to prevent them from falling, wandering, and getting lost.

*I did not feel that stressed at the beginning (when her husband first showed symptoms of dementia) when he did not forget that much and was still able to use the toilet himself, brush his teeth, wash his face, and do other things. But now he does not remember much. When he wants to use the toilet, he pees or poops everywhere, in the garden, in the open sewer, like in the old days when we were still very poor. After using the open sewer as his toilet, he covers it, washes his hands, but sometimes he takes the waste from the sewer and spreads it on the wall. So I have to watch him closely. As his illness progresses, he becomes more stubborn and I cannot control him. I am so frustrated. (CG05, Female, 71)*

The changing symptoms put more pressure on the adjustment of family caregivers. They often associated these changing symptoms with negative feelings, such as worry and frustration. Most of the caregivers were educated and warned about the progress of dementia from the health professionals at the NGH. When the symptom changes happened, they took caregivers to another level of acknowledgement of their situations and reactions.

### **Acknowledgement (A)**

The second stage of the adjustment process happened when family caregivers began to acknowledge their caregiving situations, including caregiving demands, challenges, and available resources to support their caregiving, as well as a more profound level of their identity (*the self*) in caregiving. The acknowledgement of '*the self*' in caregiving referred to how they reflected upon their beliefs, emotions, and behaviors, which shaped their identities as caregivers. It is worth mentioning that the acknowledgement of caregivers did not necessarily go with acceptance. It often required more time and effort for caregivers to transit from acknowledgement to the stages of experiments and acceptance.

***Caregiving demands, challenges, and resources.*** Caregivers confronted caregiving demands and challenges at different levels depending on the phases and severity of dementia symptoms of their loved ones. Most caregivers clearly acknowledged their intensive workload, time constraint, social isolation, and financial burdens. These burdens negatively affected their physical health and emotional states. As care recipients' symptoms changed over time along with the progress of dementia, caregivers recognized new emerging demands and challenges regarding their caregiving

duties. Furthermore, role demand and conflicts were common concerns among caregivers when they tried to balance multiple roles in their family, community, and society. Female caregivers who played a variety of roles, such as a wife, a mother, a sister, a daughter, and an employee at the same time highlighted their struggles to maintain and upkeep all of these roles along with the role of a primary caregiver for the relatives with dementia. Besides, long-term caregivers constantly dealt with increasing role demands and emerging conflicts in their families and/or workplaces as their relatives' symptoms worsened.

In addition to the demands and challenges emerging from caregiving, caregivers were well-aware of their social support. Most caregivers considered nuclear and extended family the primary and the most important informal social support during their adjustment process to the caregiving role. Besides, family caregivers placed trust and endorsed the formal social support from the professionals in the Dementia Program at the NGH. The Dementia Program was also the only specialized geriatric care they sought help from while outside healthcare services did not exist. Family caregivers acknowledged not only available resources for their caregiving, but also developed their own strategies to match available resources with identified caregiving demands. Their experiments with caregiving task strategies is discussed in the next stage of Experiment.

***The self in caregiving.*** In the stage of acknowledgement, Vietnamese family caregivers learned about their identity (*the self*) in caregiving by constantly reflecting upon their beliefs, emotions, and behaviors while providing direct, hands-on care for their loved ones. Family caregivers went through a wide range of complex beliefs, emotions, and behavior reactions during their caregiving term. Their beliefs/perception/attitude,

emotions, and behaviors constantly swung between the negative and positive spectrum as immediate responses to caregiving situations (*Figure 4.2*). On the negative spectrum, family caregivers often passively held the ‘*have-to-take-it*’ and ‘*what-if*’ attitudes when enduring the caregiving role for a relative with dementia. Particularly, caregivers recalled multiple emotional states in the negative spectrum. The extensive emotions were categorized into three levels based on their intensity. Most caregivers self-revealed their negative emotions at level 1, such as ‘*worried*,’ ‘*tired*,’ ‘*pitiful*,’ ‘*sad*,’ ‘*uncertain*,’ and level 2, such as ‘*exhausted*,’ ‘*fear/afraid*,’ and ‘*stifled*.’ A few long-term caregivers of the people with advanced dementia self-reported more extreme emotions, such as ‘*miserable*,’ ‘*shocked*,’ and even ‘*feeling like dying (inside)*.’ Their common behaviors, in response, were often comparing to the past, ignoring (the people with dementia and their behaviors), and crying. Noticeably, caregivers not only acknowledged their negative beliefs/attitudes, emotions, and behaviors, but also were able to clearly and honestly describe them in their own language:

*I called my siblings who live in my hometown. I talked and cried at the same time. Too depressed. I cried too much, and sometimes I screamed, yelled, and cursed. Sometimes I could not stand it anymore: “Terrible, you hit me?” I was a devoting traditional woman, a role model for my husband and my children, but now sometimes I become a nasty woman. Angry, then I cursed him: “You the bastard! F\*\*\* you!” I was very depressed and felt like my head was about to explode and I just wanted to die... Keep being like this, keep giving care like this, I may die soon. To be honest to you, sometimes, I just want to tell him: “I would rather have you die!” I was too hopeless and resentful. (CG05, Female, 71)*

On the positive spectrum, family caregivers also expressed a variety of beliefs/perception/attitudes, emotions, and behaviors. The most frequent and common attitude shared across discourses of caregivers was ‘*acceptance*,’ which is discussed in the last stage of this core adjustment process. A few caregivers who experienced the

improvement in the symptom management of their loved ones reported that they felt better or relieved. Most of the other cases did not show many improvements in their symptoms. Most of their caregivers, however, revealed a gradual development of understanding and empathy for the loved ones with dementia along the process of dementia progression. The most common behaviors corresponding to their beliefs, attitudes, and emotions were looking on the positive sides, planning for future, finding joys/rewards in caregiving, sharing difficult feelings with others, and focusing on the present. Depending on the care recipients' conditions and caregiving situations, some caregivers reported more negative beliefs, emotions, and behavior reactions than positive ones and vice-versa. *Figure 4.3* illustrates and reflects the most common beliefs/perception/attitude, emotions, and behaviors shared by caregivers.

Going through multiple, complex states of beliefs, extensive and intensive emotions, and behavior reactions, Vietnamese family caregivers learned about their identity or their '*selves*' in caregiving. Caregiving reconstructed their identity and the sense of self. Before taking on the role of dementia caregiver, caregivers maintained their regular social roles in the family, community, and society as a spouse, a parent, a child, a sibling, an employee, and a community member. After learning about the diagnosis of dementia, they started developing a deeper sense of their newly adjusted role. For example, a female caregiver shared her disconnection to the role of a wife and started describing herself as a spousal caregiver, a family doctor, and even a maid for her husband with dementia. The disconnection to the former role, for instance, as a spouse, led to the loss of intimacy and negative emotions, such as upset and frustration.

Tough caregiving situation tended to lead to double identity crises among Vietnamese family caregivers. Living with relatives who showed severe cognitive impairments, high dependence in ADLs, especially incontinence, and frequently disruptive or even violent behaviors, family caregivers no longer recognized their loved ones and failed to reconnect those people to their former identities they had known before. A spousal caregiver shared:

*He used to be a true gentleman. Now with this disease (AD), I feel so pity for him. He was so handsome, but now, he lost 70-80% of that charming look... I am really sad. How can I feel happy with that? We were a happy couple before. When vendors in the market (where she worked before) saw us together, they said: "Wow, look at them, they are such a sweet couple. They always hold their hands, lovingly look at each other's eyes. They love each other so much!" They even said that. But now, it is not like that anymore. (CG05, Female, 71)*

Acknowledging the loss of the former self of the care recipients contributed to the loss of intimacy and loss of self among many caregivers, particularly spousal caregivers. Most caregivers associated their identities and sense of self with their relatives' identities. Under the impact of the illness, they observed the loss of former identities of the relatives and started questioning their own identities. In other words, the loss of self of the care recipients contributed to the erosion of the self of the caregivers who were close and attached to them. At this stage, many caregivers revisited the image of the care recipient's former self with the question started with 'What if' or the assumption started with 'If.' A spousal caregiver visioned her life would have been perfect and endlessly happy if her husband had not developed dementia despite the fact that he had lived with dementia for more than 10 years. Comparing the current care recipients to their former selves in the past disconnected the caregiver from the present and acceptance.

## **Experiment (E)**

Following the stage of acknowledgement, Vietnamese family caregivers entered the stage of experiment with different strategies to adapt to the caregiving situations. Two types of experiments responding to the acknowledgement of caregiving demands, challenges, and resources, as well as the self in caregiving were caregiving task focused and self-perception focused strategies.

*Caregiving task focused strategies.* The primary goal of family caregivers was to take good care of their relatives at different stages of dementia to preserve care recipients' health. Therefore, caregivers focused on learning and trying multiple direct, hands-on care strategies, including close supervision, medication, diet, and exercise management. Caregivers prioritized medication management in their caregiving. They also emphasized the importance of a balanced and healthy diet with exercise. Even though caregivers did not have any formal training in nutrition, they self-taught to design the diet for their loved ones, such as including a vegetarian meal in a daily three-meal diet, combining with supervised walking every day. As dementia progressed, the conditions of the people with dementia constantly and unpredictably changed with new symptoms and needs. This required family caregivers to observe their relatives' conditions carefully and change their caregiving routine accordingly, including changing the diet and walking routine of the care recipients.

In order to better manage care recipients' medication, diet, and other physical and social activities, family caregivers applied a variety of personal strategies. In addition to spending more time observing and supervising their relatives, primary family caregivers actively sought for illness and caregiving related information, adjusted their schedules,



including their working time, led and coordinated caregiving tasks among other family members. To caregivers for the relatives at more advanced stages of dementia, caregiving became more time-consuming as they needed to spend extra time supervising their relatives to prevent them from wandering and getting lost. Some caregivers adapted to this situation by quitting or reducing their time for work. Along with various strategies targeting different needs of the care recipients, primary family caregivers motivated themselves to learn new skills and reinforce necessary competences and characteristics to better support their loved ones. They all shared that they practiced being more patient to their relatives, as well as learned to effectively communicate with them. For example, some caregivers learned from the advice of the psychiatrists and nurses at the NGH, and they started talking more slowly in short sentences to the care recipients. They read the signs of their loved one to pamper and negotiate with them to help them take the medicine, finish their meal and the walk. A caregiver noted about her new caregiving strategies: *“The key is to be patient.”*

In addition to being patient, caregivers showed their creativity in caregiving. Despite the lack of information, knowledge, and prior experiences of dementia care, caregivers taught themselves to adapt to the unique situations of their caregiving in innovative ways. Each caregiver developed his or her own strategies tailored to the relative’s symptoms and needs. They also came up with many creative ideas. For example, a son-in-law caregiver designed a silver bracelet with his contact information engraved in order to prevent his father-in-law from getting lost in case he might wander. A spousal caregiver designed himself a rolling bedside bucket made to his order to place under his wife’s bed. His idea came from his experience when his wife was incontinent

multiple times every night and no diaper worked for her. Other caregivers shared that they encouraged and coached their loved ones to go grocery shopping, read a book in 15 minutes every day, write a diary, make a phone call to a friend at a time, and participate in community events.

As caregivers were mostly self-taught, their creative strategies came from their rich understanding, empathy, love, and tremendous time and effort spent on direct, hands-on care for their relatives with dementia every day. Many caregivers positively revealed that they took caregiving as a chance to renew their bond with their loved ones, reinforce their family connectedness and tradition, and learn new skills. Multiple spousal caregivers shared that caregiving gave them an opportunity to pay back the love and support they had received before from their spouses, and “*start our love anew*,” as a male caregiver commented. Adult children caregivers also discussed that caregiving helped bring their siblings together to spend more time with their parents. Experiments with new caregiving tasks-focused strategies, in other words, could lead to positive and fulfilling experiences for family caregivers.

***Self-perception focused strategies.*** Through intensive hands-on, direct care for relatives with dementia, Vietnamese family caregivers not only learned and improved caregiving skills and competences, but also developed their self-perception/self-awareness focused strategies to adjust to their new identities. The development of their self-perception was based on their constant reflection upon their attitudes, emotions, and behaviors emerging from specific events. All caregivers acknowledged their negative thoughts, emotions, and unexpected behaviors toward their loved ones in chaotic and violent situations. Following the acknowledgement, most caregivers switched their

thoughts into a more positive and constructive spectrum based on their moral values. As a spousal caregiver recalled: *“Sometimes, a thought came to my mind, like: “If you die soon, we will not have to suffer any longer.” But then, my conscience guided me not to think like that.”* (CG18, Male, 77).

Along with the caregiving process, most caregivers changed their mindset and came to term with an agreement that they were not able to change their relatives’ conditions, including their cognitive impairment and disruptive, violent behaviors. Therefore, many of the caregivers decided to focus on changing their own perceptions and attitudes towards the care recipients and their situations. Instead of blaming and immediately reacting to the annoying, disruptive, and sometimes, violent behaviors of their relatives, caregivers focused on training their thoughts to shift their emotional and behavioral reactions from the negative spectrum to the positive spectrum. A male caregiver pointed out: *“Patients (with dementia) will always be patients. There is nothing else they can do. It is all about caregivers... It all depends on our mindset. We create our own mindset. We can update new information to learn which would work for us and which would not.”* (CG04, Male, 59). This thought and reaction training was often challenging. Family caregivers kept practicing these self-perception focused strategies along with the course of direct caregiving. A spousal caregiver was open about his caregiving journey for his wife:

*Some days, she hit me and I hit her back. I even punched her. I am honest to you. But then, I reflected upon that, and I tried to control myself: “No, it is not OK. I should not have done that.” Since then, I stopped doing that because I told myself: “She hit me because she did not know anything anymore. I should be gentle to her, negotiate with her, not hit her.” I am honest to you. Before, there were times I was so angry, so mad, I could not stand it, and slapped her. But after becoming aware of that, I stopped reacting to her by hitting her back around a*

*year ago. I just felt pitiful for her because she has been sick. She had no idea what she was doing. (CG18, Male, 77)*

The development of self-perception in caregiving among caregivers also led to their new perspectives in self-care. Long-term caregivers of relatives with advanced dementia learned about the importance of self-care after reflecting upon their frequent negative emotional and behavioral reactions towards their loved ones and caregiving situations in general. A long-term caregiver who has cared for her husband for than 10 years reported that recently, she started going to a hair salon or a tea shop in her neighborhood twice a week to relax, ‘*relieve stress,*’ and ‘*free herself*’ from ‘*going crazy*’ with constantly cleaning after her husband. Similar, another long-term caregiver shared about his reclaim of self-care:

*I try to be nicer to myself. If my children visit me, I tell them to stay with their mother for a while so that I can travel to somewhere nearby. For my own sanity. Caregivers like me need to keep our mind light and content. It is very dangerous if we are sad and depressed, because we may be sick. I see that already. I have my own strategies to take care of myself and improve my life in order to take care of her better. (CG18, Male, 77)*

From caregivers’ perceptions, reclaiming self-care was not only for the benefits of the caregivers, but also for the caregiving outcomes in long-term. Novice caregivers did not focus on self-care at the beginning stage of their dementia caregiving as they tended to devote and sacrifice for their loved ones with dementia and their family as a whole. Only long-term caregivers for the people with late dementia clearly acknowledged the need of self-care when they reached the point of burnout and serious health deterioration. Adopting new strategies to spend personal time and relax helped caregivers shift their thoughts to a more constructive, positive spectrum. As a result, they started experienced

more positive emotions, which contributed to their acceptance of the role, situation, and the new self in caregiving.

### **Acceptance (A)**

Emerging from the data, acceptance referred to not only an ultimate goal, but also a final stage of the learning process which most family members went through to adjust to the illness of their loved ones, their caregiving role, and the new self/identity in dementia care. Acceptance was the most frequent and significant key category detected across discourses of caregivers (*Figure 4.3*). Vietnamese family caregivers entered the stage of acceptance when they started viewing their reality as it was. There were multiple shades and levels of acceptance. In this study, family caregivers mostly presented two types of acceptance, including passive acceptance and active acceptance.

***Passive acceptance.*** Many caregivers accepted the illness of their loved ones and their caregiving situation in a passive way. Those caregivers tended to associate dementia with the fate of the relatives. They also associated their caregiving roles, including caregiving demands and challenges, with their fate. A female caregiver commented: “*Because it is my fate, I accept it.*” (CG01, Female, 56). Using the term ‘*fate*’ to describe their situation, caregivers tended to hold less hope and be inactive in actions as they perceived that “*there was nothing else to do*” to improve the situations or their feeling stemming from the situations. As a result, they maintained their caregiving duty with the goals of ‘*getting through it*’ and ‘*getting it done*’ on a daily basis.

Cultural values and religious and spiritual beliefs played a significant role in shaping the passive acceptance of family caregivers in dementia care. First, Confucianism-based values of filial piety for adult children, as well as affection and

gratitude among spouses established moral standards for family members to undertake the role to fulfill their social responsibilities and expectations of a good filial child or a devoted spouse. Taking the role of a primary caregiver for the loved one with dementia was also considered a method to ‘*save face*’ or protect social pride and reputation of the whole family and its members, which was associated with familism (Miyawaki, 2015). Under these social expectations, most caregivers found no other way than accepting their roles, regardless of their attitudes and emotions. While most of the family caregivers accepted their role voluntarily and willingly with pride and honor, a few caregivers expressed their obligational or unwilling acceptance. Second, Buddhist beliefs of karma (the law of cause and effect) and good deeds sowing and reaping for the whole family becomes a way of life to most Vietnamese people regardless of their religious status. As a result, many caregivers adopted these Buddhist beliefs to make sense of their relatives’ illness from the approach of a karma. They collectively explained that having dementia was a karma to not only a care recipient, but also to the whole family, including the caregiver. Therefore, enduring caregiving duties with its difficulties was a way for them to pay back the ‘*debts*’ from their previous lives. Even though they still experienced multiple negative emotions associated with their daily caregiving activities, they accepted their situation and tried to “*get by*.” Buddhist beliefs contributed to shape not only passive acceptance, but also active acceptance, depending on the interpretation of each caregiver. The influences of Buddhist beliefs on caregivers’ active acceptance are discussed later in the section of caregivers’ beliefs and commitments to caregiving.

***Active acceptance.*** Family caregivers who actively accept their caregiving role and situation acknowledged and came to term with the fact that dementia was a difficult

condition to deal with and it would progress with constant symptoms changes. They, therefore, accepted caregiving demands and its challenges as their reality, and at the same time carried realistic views and hope in their practical, feasible, and flexible action plans. They considered the illness of their loved ones and the difficulty of caregiving part of the ordinary life which was always unpredictable, yet there were room for improvement and development. They described life as a combination of unpredictability, risks, misfortunes, as well as joys, hope, and chances for personal growth. These caregivers accepted life situation with its duality and uncertainty, and with active actions to respond to caregiving situations. To these caregivers, active acceptance was a choice. A spousal caregiver expressed: *“I take what life gives me. I accept everything and try my best to live with a positive attitude. Living with a burden in my heart just makes it harder. I learn to live with adversity.”* Furthermore, these caregivers turned their caregiving experiences into life lessons and gracefully and gratefully accepted and embraced them as part of their lives:

*I accept it. When I decided to take him (father-in-law) to live with us here, I already accepted the challenges going with it. My life routine was interrupted at first, but I will get used to it eventually... I am content. Being born, getting old and sick, and passing away are the rules of life which each of us will experience. As a child, I try my best to take care of him. When he passes away, I may cry, but I cannot keep crying for the rest of my life. (CG08.1, Male, 34)*

Active acceptance includes both the cognitive process and the actual actions of family caregivers to cope with their caregiving challenges. Cognitively, caregivers assessed their situation as it was instead of awfulizing or ‘pink-clouding’ it. Grounded hope played a key role in active acceptance. Grounded hope referred to practical expectations based on a realistic view of life situations (Feldman & Kravetz, 2015). Holding grounded hope, Vietnam family caregivers refrained from carrying unrealistic

wishful thinking, such as their relatives would be totally cured of dementia one day. Instead, they tried their best to take care of the loved ones, made plans for future, including the plans for the worst scenarios, found joys and rewards in caregiving every day, and focused on the present. A spousal caregiver shared about his cognitive process and actions when actively accepting the situation:

*We cannot predict anything. There is an old saying: "Things won't happen the way you say it would." Do not worry about it. What will come, will come. I only try to do what under my control... I am at the age of 60, it does not matter if I worry or not. I only focus on what I know best and take the best care of my wife to help her improve as much as possible. I do not think too much, just do my best.* (CG04, Male, 59)

Coming to the stage of active acceptance, family caregivers were more content with their caregiving situations, including both demands and achievements. They learned to appreciate and show gratefulness for small achievements in daily care, such as when their loved ones ate and slept well. They were also more flexible in their caregiving strategies and plan, and accepted changes in their relatives' symptoms and plans more easily: *"If her illness gets worse tomorrow, I will adapt my caregiving routine to meet her needs. I do what I can. What I cannot do, I accept that too."* (CG19, Male, 75). They were also more realistic in assessing their caregiving abilities (what within and out of their control), and content with their limitations. When caregivers progressed to the stage of active acceptance, they stopped blaming and victimizing themselves over their limitations in caregiving. Instead, they found their limitations room for learning and improvement. This attitude released family caregivers from extreme negative emotions, as well as allowed them to experience caregiving in a more positive, fulfilling way. It did not mean that progressing to the active acceptance stage totally excluded caregivers from experiencing negative feelings arousing from their daily caregiving activities. They,



however, embraced their feelings, including positive and negative ones, and learned to make peace with their inner self. Unlike caregivers who still stayed in the previous stages and denied accepting their roles and caregiving situations, caregivers with active acceptance did not show the symptoms of depression, destructive self-concepts and emotions, such as '*feel like dying*.'

### **Personal factors influencing the EAEA process**

Personal factors influenced the EAEA process which Vietnamese family caregivers went through to adjust to their caregiving role for a relative with dementia. Personal factors of caregivers included: (1) demographic and relationship characteristics of caregivers with the care recipients; (2) their personal beliefs and commitments to the care recipients and caregiving; and (3) personal history of caregiving and coping with adversity in the past. Among these three factors, personal beliefs and commitments, as well as personal history of caregiving and coping with past adversity played more important roles in shaping the adjustment process, particularly the acceptance of caregivers.

#### **Demographic and relationship characteristics**

Participants in the study were diverse with different socioeconomic backgrounds of ages, genders, educational levels, employment status and jobs, and geographic areas of residence (*Table 4.1*). Different backgrounds impacted caregivers' experiences in caregiving in some specific aspects, such as challenges in providing medical care for their loved ones and their access to social support. For example, one third of the participants lived in the rural areas where they did not have access to high-quality healthcare services and related information. To receive the specialized services at the NGH, many caregivers

and their relatives had to travel for a long distance every month which caused them a significant amount of money and time. This challenge became more critical when most of the caregivers were retired and lived on a tight budget. Not all the retired caregivers had retirement pension as a few of them were farmers. Some of them still worked on the farm or found a part-time job to continue supporting themselves and their relatives with dementia. These challenges influenced their experience of the illness and hands-on care, as well as their acknowledgement of caregiving situation in their context, and navigated their experiment with caregiving task focused strategies.

Relationship characteristics of the primary caregivers with the care recipients, secondary caregivers, and other helpers played a more significant role than their own demographic characteristics in shaping their EAEA process. Caregivers who had the direct bloodline or marital relationship with the care recipients, such as a child or spouse, tended to take on the role as a primary caregiver without hesitation or resistance. On the other hand, a caregiver who took care of her mother-in-law with advanced dementia showed her negative emotions toward taking the role. She argued that her three sisters-in-law, who had the direct bloodline connection with the care recipient, should have taken on the role of the primary caregiver. She undertook the primary caregiver role passively and psychologically denied accepting her life situation. In addition, the relationship of the primary caregivers with other family members contribute to define their social support, which critically influenced the adjustment process to their role. Caregivers residing in the rural areas with strong cohesion with their extended family often received help for specific caregiving duties, such as supervising the people with dementia for a few hours when the caregiver needed to leave the house. Caregivers who received meaningful social

support from family showed that they smoothly progressed across the four stages of the process and learned to accept their role and life situation quite actively.

Even though demographic and relationship characteristics influenced the adjustment process of Vietnamese family caregivers to their caregiving role to some extent, the influences of the demographic characteristics were not consistent across cases of caregivers. In fact, the data showed that most caregivers with lower educational levels, lower income, and lived in the rural areas progressed smoothly over four stages of the EAEA process and actively accepted the illness of their loved ones, their caregiving situation, and role. Emerging from the data, caregivers' mindsets based on their personal beliefs and commitments, as well as their personal history of caregiving and coping with adversity in the past played much more important roles in shaping their adjustment process to caregiving role.

### **Personal beliefs and commitments**

Personally beliefs of Vietnamese family caregivers, including their beliefs in family responsibility in caregiving and religious and/or spiritual beliefs, pivotally shaped their commitment to the caregiving role and impacted the adjustment process to this role. Caregivers holding values of family responsibility/obligation in caregiving, affection and gratitude (between husband and wife), and filial piety (between children and parents) tended to take on the role and carry it out easier. Based on these values and beliefs, they developed and strongly held on their commitments with their relatives. Their commitments in caregiving for their loved ones with dementia were associated with their morality, conscience, identity, and social reputation. They also considered themselves role models for other family members. In other words, family caregivers with strong

personal beliefs in and commitment to caregiving role often found the constructive meaning of caregiving and accepted their caregiving role with joys and appreciation.

In addition to the value-based personal beliefs of family responsibility in caregiving role, spiritual beliefs also contributed to caregivers' acceptance of their role and caregiving situations. Not only did Buddhist beliefs influence caregivers' passive acceptance, as discussed previously, they also contributed to shape caregivers' active acceptance. Even though most caregivers self-reported that they were not associated with any specific religion, most expressed their spiritual beliefs to some extent. Particularly, most caregivers shared their Buddhism-based belief of karma, or the rule of cause and effect of an action, and the crucial practice of compassion and good deeds. They adopted these beliefs to explain their situations and accept it with ease. These beliefs directed them to pray and do good for others, including their loved ones with dementia, to collect good karma and find peace for themselves. During the adjustment process, caregivers acknowledged their selves in caregiving, including their own beliefs/perception/attitudes, emotions, and behaviors swinging between the negative and positive spectrums. Spiritual beliefs, particularly Buddhism-based beliefs, helped them navigate their beliefs, attitudes, emotions, and behaviors toward the positive spectrum more often in the challenging situations related to direct care provision for their relatives. Family caregivers with strong spiritual beliefs tended to focus on changing their own negative perception and attitudes toward the people with dementia and their difficult situations, leading to their deeper understanding of their "selves" and acceptance of their situation.

### **Personal history of caregiving and coping with adversity**

Personal history of caregiving and coping with adversity in the past played the key role in shaping the adjustment process of Vietnamese family caregivers to their caregiving role, as well as their acceptance of their situation. Most of the caregivers in the study had confronted multiple adversities in their lives. Particularly, two third of the caregivers were at the age of 55 and above. Most of the older caregivers in the study experienced the effect of the Vietnam War (also known as American War among Vietnamese people) directly or indirectly. Living with poverty, hunger, physical injuries, chronic diseases, as well as loss of family members and war trauma were common among older caregivers. In addition, some younger female caregivers experienced different types of psychological difficulties from their marriage and family conflicts, including separation, divorce, and family disconnection. Overall, many of the family caregivers were traumatized with different major events in their lives. Confronting all of these adversities at younger ages, Vietnamese family caregivers developed their coping skills and resilience. “*I lived a very tough life when I was a child. That’s why I get used to adversity now.*” (ID16-CG08.2). Notably, caregivers who experienced the most challenging situations, even traumas, in their lives all revealed their growth mindset with significant sources of strengths despite their backgrounds of socioeconomic status. The sharing of the following caregiver was typical among caregivers who have confronted multiple adversities in their lives:

*Since I was born, I have been living with so many sufferings. So now I can live with all kinds of suffering because I see suffering a normal part of life. I was an orphan since I was so little. I learned to take care of myself since then... My mother passed away when I was 12, my father had passed away before I could even remember his face. I have siblings... I had suffered a lot during my childhood, especially from hunger. I used to have nothing to eat and only lived on*

*a few kilograms of rice provided by the communal cooperative... Getting out of poverty, I feel so lucky. That is why I am positive. It is all in my head. I tell myself this: "If I keep thinking, it only makes me suffered." If I let it go and keep working, I will overcome it. (CG12, Female, 68)*

Not only past experiences of living and coping with adversity, but also history of care provision for others shaped the adjustment process of Vietnamese family caregivers to their caregiving role. Most of female caregivers in the study shared their long history and rich experiences of caregiving for other family members, which maps onto the cultural values of devotion, self-sacrifice, and familism, as well as the social norms toward female family members in Vietnamese society. Many of them became para-professional caregivers without payment for their family members who were in need. For example, a female caregiver shared her long history of caregiving for other family members when they stayed in the hospital. She took care of her sisters-in-law and daughters-in-law after they gave birth, and her siblings and cousins with terminal illness. She started her caregiving role for other family members at a very young age:

*I always take care of my siblings and others. I also took care of my sisters-in-law when they gave birth... My life has been tough since I was so little. I even had to run to the jungle with my family when (American) airplanes dropped bombs in my hometown. From the age of eight or nine, I went to the hospital with my mother, took care of others, and waited for her to give birth... I have lived with a very rough life since I was little. I was always working and helping my mother to take care of other siblings. I took care of myself. I did not have time to play, I had no childhood and no youth. Then I got married, but my husband and I separated from each other when my children were still very small. He lived with another woman, but did not divorce with me. (CG09, Female, 54)*

Going through multiple adversities and caregiving demands from other family members, Vietnamese family caregivers gradually developed their resilience, growth mindset, and coping skills, which then were applied to adjust to the caregiving role for a relative with dementia. They still confronted negative thoughts, emotions, and behaviors

toward their relatives in intensive and challenging situations when the people with dementia exposed extremely disruptive and violent behaviors toward them, such as biting, pushing, and hitting. They, however, gradually enhanced their sense of self in caregiving and learned to move toward the positive spectrum. They also quickly and actively accepted the illness of their loved ones, their caregiving role, and uncertain life situations. On the other hand, some other caregivers who did not experience major adversity in their lives before tended to reveal more negative thoughts, emotions, and behaviors, as well as disconnect with and deny the reality of the illness and caregiving situation. Among the three personal factors, the two latter factors, including personal beliefs and commitments, and particularly personal history of caregiving and coping with adversity in the past, played critical roles in shaping the EAEA adjustment process of Vietnamese family caregivers to their caregiving role.

### **Structural factors influencing the EAEA process**

In addition to caregiver personal factors, structural factors, including cultural values and norms, social pressure, and social support, impacted the adjustment process of Vietnamese family caregivers to their caregiving role for older adults with dementia. These structural factors also interacted with personal factors to collectively influence the adjustment process of caregivers. For example, the cultural value of filial piety crucially shaped adult children caregivers' beliefs in and commitments to caregiving for their older parents.

#### **Cultural values and social norms**

Cultural values and social norms significantly contributed to shape the adjustment process of Vietnamese family caregivers to their caregiving role. The key Confucianism-

based values shared by family caregivers included familism (family harmony and cohesion), filial piety among children caregivers, and affection and gratitude among spousal caregivers. All Vietnamese family caregivers agreed that taking care of an older adult with dementia was primarily family responsibility, and the primary caregiver should be adult children, particularly the oldest child, and/or the spouse depending on his/her health condition. This perception was also widely accepted in the community. A female caregiver commented on the caregiving norm in her community: *“Whenever a parent is sick, children will voluntarily take care of him/her.”* (CG02, Female, 53). Participants in this study all highly upheld these traditional, cultural values. As a result, they automatically and voluntarily took on the role to fulfill the social expectation associated with their roles. A female caregiver, who was the oldest daughter in the family commented:

*The key issue is the harmony and bonding within the whole family and then the society. Luckily, my father has the support from our family. Although he has daughters only, we all know how to take care of our parents. Each of us carries a specific duty. We divide our tasks and I coordinate them among my siblings. Everything runs smoothly.* (CG10, Female, 44)

Family caregivers’ attitude toward the role of a primary caregiver, however, varied across cases depending on the level of social support they received from other family members. As familism played a pivotal role in family caregivers’ perception, they did not only try to devote and sacrifice for their loved ones with dementia and their families, but also expected the voluntary support from their family in caregiving activities. Having great support from other family members in caregiving was perceived as a strong evidence of having a cohesive, bonded family, which family caregivers were proud of. They also used this as a criterion to assess social reputation of the whole family



(save face), including social reputation of each of its members. Primary caregivers with significant family support adjusted to caregiving demands and changes in care recipients' symptoms quickly. On the contrary, without adequate and willing support from other family members, family caregivers found it more challenging to adjust to the caregiving role.

### **Social pressure**

Cultural values and norms facilitated the adjustment process and acceptance of the caregiving role and situations of Vietnamese family caregivers, yet contributed to social pressure and judgment which, on the other hand, inhibited this process to many caregivers. Social pressure and judgment came from both family and community and mostly placed on female caregivers. Vietnamese people shared the common gender norm which expected women to take care of other family members, including their spouse, children, parents, and sometimes even other members in the extended family. Women were also considered a contributor to the income source of the household. Female caregivers, therefore, tended to carry multiple demanding roles at the same time. Their roles were associated with a variety of expectations at different levels. This often led to role conflicts to most female caregivers and burnout to some of them.

Female caregivers with frequent and significant social support, particularly from their families, had a better chance to adapt to and accept their caregiving role and situation than those who did not. When female caregivers acknowledged the caregiving demands and challenges, including role conflicts, they also identified available sources of social support to cope with the pressure. Emotional support from family, such as their spouses, children, and siblings, reduced their pressure and emotional burden, as well as

fostered them to develop and apply caregiving task focused and self-perception focused strategies, including self-care. As a result, these female caregivers progressed to their acceptance of their role as primary caregivers easier. In contrast, a few female caregivers acknowledged more judgment than empathy from other family members and community on their caregiving and struggled to move to the stage of acceptance. A female caregiver expressed her frustration and resentment due the lack of empathy and full of judgment from her neighbors, despite her great effort to take care of her husband with late dementia: *“Neighbors around here, when they heard me yelling at my husband, they thought I treated him badly... I am angry when they judge me like that... I just wanted to tell them that no one wanted to be like that. It is difficult to explain for myself.”* (CG05, Female, 71).

Social pressure and judgment from family and community inhibited the psychological adjustment process of family caregivers to their caregiving role because they created more conflicts and difficult feelings in the development of the self-concept of the caregivers. Throughout the caregiving process, the family caregivers explored different layers of their *‘inner selves’* and identities. Many caregivers had to constantly face challenging caregiving situations. For example, some spousal caregivers had to bathe and clean up after their spouses with problematic toileting and violent behaviors. They sometimes questioned their love and commitment to their loved ones, particularly after their immediate and violent reactions to the spouses with dementia, such as hitting back. Caregivers in these situations went through their own identity crises of *‘the people they thought they were’* versus *‘the people they have become.’* A spousal caregiver compared her former self as a *‘loving, devoted woman’* to her *‘becoming nasty woman’*

under the intensive burdens of caregiving for more than 10 years. Family caregivers like her already struggled to come to term with their new '*selves*.' Outside pressure and judgment would likely make their adjustment to the new '*selves*' more difficult.

### **Social support**

As can be seen from the previous section, the structural factor of social support played a very critical role in shaping the adjustment process of Vietnamese family caregivers to their caregiving role for an older adult with dementia. Social support included both formal support from the NGH and informal support from their nuclear and extended families, friends, and neighbors. Family caregivers received social support in different forms, including tangible support (money and supplement for patients with dementia), informational support from those who were knowledgeable in medical care, and emotional support from family and friends during the caregiving process.

The availability and frequency of social support a family caregiver received impacted how he/she progressed across stages of the EAEA process. Caregivers with multiple sources and forms of social support had better means to cope with caregiving demands and challenges. They had a variety of choices for their experiment with caregiving task focused and self-perception focused strategies. For example, caregivers living in big cities with more options of care services, such as house-maid, could obtain more time for self-care. On the other hand, caregivers living in rural areas with strong support of extended families found it easier to ask for help with hands-on care in some specific situations. In general, family caregivers with good social support tended to progress across stages of the EAEA process easier and actively accept their caregiving role and situation with better action plans. Other caregivers who did not receive

significant social support, particularly from their families, often struggled during each stage of the process. Those caregivers often debated with their own beliefs, emotions, and behaviors related to caregiving duties. They tended to experience more negative aspect than positive aspect in their perceptions and emotions and found it harder to balance between the two spectrums and learn to really accept their caregiving role and situation as part of their reality.

### **Summary of the transactional model of the adjustment process to caregiving role**

The adjustment process of Vietnamese family caregivers to their caregiving role for their loved ones with dementia is a multiple-stage process which happens in a transactional relationship between caregivers and their environment. A transactional relationship refers to a “*dynamic, mutually reciprocal, and bidirectional relationship*” between caregivers and their environment (Lazarus & Folkman, 1984, p. 293). *Figure 4.4* summarizes the transactional model of the core adjustment process (the EAEA process) of Vietnamese family caregivers and its interaction with personal and structural factors.

The core psychological adjustment process, or the EAEA process, is an iterative cycle of four stages, including (1) *Experience* of the symptoms and hands-on caregiving activities; (2) *Acknowledgement* of hardship and changes of the self in caregiving; (3) *Experiment* with strategies for providing care to the relative and strategies for self-care; and (4) *Acceptance* of the caregiving situation and role. Caregiver personal factors consist of their demographic and relationship characteristics with care recipients; personal beliefs and commitments in caregiving; and personal history of caregiving and coping with past adversity. The structural factors of family caregivers include cultural

values and norms; social support; and social pressure. Caregivers' personal and structural factors interact with each other to impact their psychological adjustment process.

The adjustment process to the caregiving roles of Vietnamese family caregivers has different layers. Family caregivers did not only adjust to their role and caregiving situation and demands, but also to their new '*selves*' and identity. The adjustment process, in other words, is a process to explore the self at more profound levels. This process placed family caregivers in difficult situations which required them to constantly acknowledge '*the persons they thought they were*' and '*the persons they have become*' in chaotic and problematic situations. This process also fostered them to learn to come to term with the complex perceptions, emotions, and behaviors they had, as well as accept the situation and embrace their '*becoming selves*.'

## **DISCUSSION**

A large body of research has been devoted to examining the coping process of family caregivers to respond to the stressful caregiving demands in dementia care, such as the caregiving and the stress process (Pearlin et al., 1990) and the stress and coping model (Lazarus & Folkman, 1984). Particularly, the stress and coping theory (Folkman & Lazarus, 1984), which consists of (1) stressors; (2) cognitive appraisal; (3) coping strategies; and (4) adaptation outcomes, has been adopted broadly across populations with different health problems. This theory particularly highlights the cognitive appraisal with two different levels, including primary and secondary cognitive appraisal. Primary appraisal refers to caregivers' assessment of risk factors, such as potential threats to the well-being of himself/herself or the loved one (Aranda & Knight, 1997; Folkman & Lazarus, 1984). In this appraisal, individual characteristics, such as "*values*,

*commitments, goals, and beliefs about oneself and the world,”* are applied to assess the risks in a specific stressful transaction (Folkman & Lazarus, 1984; Folkman et al., 1986). In secondary appraisal, the caregiver assesses a variety of solutions or possibilities to overcome the problematic situation (Folkman & Lazarus, 1984; Folkman et al., 1986). In the primary appraisal phase, caregivers assess the distress level of the situation, while in the secondary appraisal phase, they assess their self-efficacy, or their beliefs and confidence in their ability in managing problems (Bandura, 1977, 2010; Haley et al., 1987).

In addition, the caregiving and the stress process (Pearlin et al., 1990) and the sociocultural stress and coping model (Aranda & Knight, 1997; Knight & Sayegh, 2010) discuss multiple factors influencing the coping process of family caregivers, such as their socioeconomic characteristics, cultural beliefs and commitments, and social support. A variety of studies on family caregivers from different contexts also report the same associated factors (Gilhooly et al., 2016; Hawken et al., 2018). For instance, Vietnamese immigrants in the United States also shared the influence of Buddhist beliefs on their approaches and motivations to caregiving. Key concepts, such as karma, blessing, grace, and peace of mind were associated with their acceptance to their caregiving. Acceptance was considered their core orientation to life which helped them feel free from unnecessary worry (Hinton, Tran, Tran, & Hinton, 2008).

This study on Vietnamese family caregivers highlights the coping processes introduced in these models. To be more specific, the four-stage EAEA process and its influencing factors at both personal and structural levels are consistent with the existing stress and coping models. On the other hand, the key contribution of this study is the

emphasis and findings on '*the self*' of the caregiver in their adjustment process. The adjustment process of Vietnamese family caregivers to their caregiving happens at different layers. The first layer is their adjustment to the illness condition and caregiving demands. In a deeper layer, their adjustment process is a journey to explore and learn to accept '*the becoming of the self*.'

Self-concept, self-identity, and self-acceptance were found as the core concepts of the adjustment process, as well as of the contribution of this study to the literature. The stage of acknowledgement reveals deeply what caregivers learned about their own beliefs/perception/attitudes, emotions, and behaviors. Particularly, the acknowledgement of the self in caregiving in the EAEA model clearly portrays the coexistence and swinging pattern between the two spectrums (negative and positive) of caregivers' states. To many caregivers in the study, caregiving for the loved one with severe dementia became a form of trauma. Caregivers rarely stayed on one spectrum of solely negative or positive thoughts, emotions, and behavioral reactions. Indeed, they went through and learned about their shift in worldview and complex, divergent states in their stream of emotions. Feldman and Kravetz (2015) consider emotional upheaval part of life experiences of those who live through traumas.

Comer (2015), an American family caregiver, recalled the same swinging pattern between two spectrums of thoughts, emotions, and behavioral reactions in her account of caregiving for her husband with severe dementia. Frequent negative emotions, including worry, anger, uncertainty, emptiness, depression, isolation, fear, guilt, frustration, as well as feeling locked and trapped in the role emerged across her discourse (Comer, 2015). On the other hand, she revealed her thankfulness for her husband, and her tactics to move to

the positive spectrum by keeping herself going, finding joys, and living in the moment (Comer, 2015). Despite contextual and cultural differences, the study results of Vietnamese family caregivers' acknowledgement of the self of the caregiver with complex beliefs, emotions, and behavioral reactions in two spectrums are consistent with Comer's account (2015), as well as the findings of Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch (1995) that caregivers tend to experience positive changes in self-concepts, including higher awareness of inner strengths, self-confidence, personal growth, skill enhancement.

The consistency of the key results of this study, particularly the self-concept, identity, and acceptance of Vietnamese family caregivers in their adjustment process to caregiving role for a loved one with dementia, with study results in the Western contexts reflects the universal truths of human suffering, coping patterns, and resilience development across the context and cultures. For example, existing literature also reports the sense of loss in dementia care among family caregivers in the Western context. The sense of loss refers to not only the loss found in care recipients' functions and identity, but also the loss in caregivers' identity (loss of self or self-erosion, Aneshensel et al., 1995). These situations of double identity crises are consistent across studies in which long-term caregivers face different demands in daily caregiving and changes in their loved ones' symptoms (Butcher et al., 2001; Gillies, 2012; Hooley & Hoffman, 1999; Silverberg, 2006) and the personal account of Comer (2015). Comer (2015) reflected in her account the feeling of "*slowly losing pieces of my husband*" (p. 81) which gradually turned him into someone who was "*not the man I fell in love with and married*" (p. 1).



Experiencing self erosion in both their loved ones and themselves, caregivers confront complex feelings of loneliness, uncertainty, and unmooring.

Building upon the self-concept of family caregivers, the results of this study emphasize self-perception focused strategies which are unique from existing studies. Previous studies focus on examining the coping process, strategies, and techniques with regard to help-seeking from the formal support, such as professional healthcare services (Butcher et al., 2001; Levkoff, Levy, & Weitzman, 1999; Quayhagen & Quayhagen, 1996). This study provides evidences to extend not only similar strategies, but also specific strategies for self-awareness and mindset development of Vietnamese family caregivers. Those strategies significantly contributed to their acceptance of the illness, caregiving situation, and primary caregiving role in the family.

Acceptance emerged from this study as both the ultimate goal and the final stage of the adjustment process of Vietnamese family caregivers. In the same line with this result, Kübler-Ross (2014), in her work on death and dying, argues that family members of relatives with terminal illnesses go through the basic five stages, including (i) denial and isolation, (ii) anger, (iii) bargaining, (iv) depression, and (v) acceptance, to adjust to their situation. Acceptance, from Kübler-Ross's perspective (2014), is “*the final rest before the long journey*” (p. 124) and also considered the last stage of the adjustment process which happens when family members “*gradually face the reality of impending separation*” (p. 177). Systematic reviews of empirical studies on family caregivers’ coping in dementia in diverse contexts consistently report the use of acceptance in coping and adjusting to their caregiving role and situations (Gilhooly et al., 2016; Hawken et al., 2018).

This study reveals two main types/levels of acceptance, including passive acceptance and active acceptance. Different from passive acceptance, which was often associated with less hope and inactive action plans, active acceptance referred to the acceptance of life situation with its duality and uncertainty, as well as with grounded hope and active actions to respond to the emerging situations. Feldman and Kravetz (2015) share similar findings in their comprehensive research on the experiences of supersurvivors, who successfully overcome traumas in their lives. By interviewing different people who confronted terminal illness, loss of loved ones, severe stigma and discrimination, Feldman and Kravetz (2015) point out the common surviving formula as a combination of truly acceptance of the reality as it is and grounded hope to guide actions across supersurvivors. Kübler-Ross (2014) shares the same insight with regard to people facing death and dying. True acceptance means adopting a realistic view to live with all aspects, including its uncertainty and fragility (Feldman & Kravetz, 2015). Feldman and Kravetz (2015) also emphasize grounded hope based on honest understanding of reality to enable people to act and achieve their goals for life improvement.

Another contribution of this study is the emphasis on the roles of personal and structural factors in shaping the adjustment process. At the personal level, demographic and relationship characteristics, personal beliefs and commitments, and personal history of caregiving and coping with adversity were found to contribute to the adjustment process of Vietnamese family caregivers to their caregiving role for the loved ones with dementia. Previous studies also confirm the role of caregivers' demographics, relationship with care recipients, as well as beliefs and commitments to caregiving in

shaping the core adjustment process (Aranda & Knight, 1997; Folkman & Lazarus, 1984; Hinrichsen & Ramirez, 1992; Huang et al. 2006; Kramer, 1993; Pinquart & Sörensen, 2005). This study particularly emphasizes the role of personal history of caregiving and coping with past adversity in family caregivers' adjustment to dementia care. The results show that this factor considerably influenced caregivers' acceptance of their role and situations. This result maps on what were found among trauma survivors (Feldman & Kravetz, 2015). Feldman and Kravetz (2015) refer this factor to '*posttraumatic growth*' or '*psychological gains*' or '*inner strengths*' developed through the experiences of living with adversities.

At the structural level, this study reveals the importance of social support, cultural values and norms, and social pressure as both facilitators and hinderers to the adjustment process to dementia care among Vietnamese family caregivers. These results are consistent with existing literature which examine social support (Folkman & Lazarus, 1984; Feldman & Kravetz, 2015; Haley et al., 1987; Haley et al., 1996; Huang et al., 2006; Knight & Sayegh, 2010; Pinquart & Sörensen, 2005; Roth et al., 2005) and cultural mechanism (Aranda & Knight, 1997; Feldman & Kravetz, 2015; Folkman & Lazarus, 1984; Haley et al., 1987; Haley et al., 1996; Huang et al., 2006; Knight & Sayegh, 2010; Montoro-Rodriguez & Gallagher-Thompson, 2009) in caregiving experience across populations and contexts. Particularly, Feldman and Kravetz (2015) suggest social support to be one of the greatest factors shaping the adjustment process and acceptance of people going through adversity. In the context of Vietnamese culture, family is identified the primary social support which facilitates and inhibits caregiving at the same time as it plays as both the source of help provision and pressure and stress, especially to women.

These results are consistent with Vietnamese American caregivers in dementia care, reflecting the dominant influence of culture across geographic settings (Meyer et al., 2015).

## **LIMITATIONS**

Despite important contributions, this study has its limitations. First, the sample size of this study is relatively small and quite homogeneous. A total of 20 family caregivers who self-identified as primary caregivers and recruited from the same Dementia Program at the NGH. One can assume that these participants would be more knowledgeable in dementia compared to those who had not taken their relatives to the hospital for dementia diagnosis and treatment. The results of this study, therefore, cannot take into account experiences of Vietnamese family caregivers who did not know about dementia clinically or receive medical care from professional dementia healthcare providers. In addition, all participants resided in the North of Vietnam which meant they were likely to share the same regional culture which may be different from other parts of the country. On the other hand, the sample size and homogeneous characteristics of participants in this study are appropriate for reaching theoretical saturation in a grounded theory study (Guest et al., 2006).

Second, language translation may create a challenge for the meaning transfer of the study. The data collection and analysis were conducted in Vietnamese, the native language of the participants. Only the result synthesis was conducted in English. Some specific terms and proverbs were challenging to convey fully from Vietnamese to English due to cultural differences. For this reason, conducting data analysis in the original language helps guarantee the cultural and linguistic authenticity in the meaning transfer

of the data (Haidar, 2013; Shibusawa & Lukens, 2004). Furthermore, validity checking conducted by the two Vietnamese American committee members help address the validity threat to data analysis and synthesis.

Third, the rapport built between the researcher and the participants, as well as the ‘*therapeutic effect*’ of the interviews might influence their adjustment process to some extent (Morecroft, Cantrill, & Tully, 2004). Several caregivers shared that they ‘*felt better*’ after the interviews because the researcher listened to them. Specifically, a female long-term caregiver was interviewed in total three times over the period of six months to examine the changes in her cognitive and behavior adaption. In the first interview, she reported high risks of depression and self-destruction thoughts and extremely negative emotions, such as depressed and feeling like dying. Following the agenda approved by the USC’s IRB, after the first interview, the researcher referred her to a mental health service to address her mental health problem. She reported an improvement in her physical and mental health after receiving the treatment. Besides, she emphasized the lack of understanding, empathy, and emotional support from her family members as her biggest stressors in her caregiving. She commented on the effect of the interviews as a channel for her to be open and express her feelings freely. Within six months, this caregiver showed significant progress toward acceptance of her situations. The interviewing effect and the rapport between the researcher and the caregiver possibly play a part in her adjustment process. Therefore, the results of the study also need to take into consideration this effect.

## CONCLUSION AND IMPLICATIONS

In summary, given the critical knowledge gap in understanding Vietnamese family caregivers in dementia care, it becomes pivotal and urgent to learn about the psychological process through which Vietnamese family caregivers adjust to their caregiving role for their loved ones with dementia in their own sociocultural context. By attending to the nexus of individual experience, transactional processes, and cultural context, this research may provide an important new framework for examining transition into the caregiving role more generally. The specific results regarding the role of the “self” in caregiving, acceptance, and post-trauma growths significantly contribute to the existing literature examining resilience and coping attributes of family caregivers. Not only do these results have implications for cross-cultural studies, they can also inform interventions development targeting resilience for diverse family caregivers in a broader context.

The results of this study call for future study to deepen the understanding of ‘*the self*’ and inner strengths of Vietnamese family caregivers to adjust to the hardship of caregiving situation. More studies on experiences of this unique group in their own context are much needed. The need of these studies becomes more pressing in the changing context of demographic transition and family dynamics change due to migration trends from rural areas to urban areas in Vietnam.

In addition, the study results imply and advocate for the needs of culturally competent interventions and social services targeting family caregivers. The role of social workers should be explored in the development and implementation of interventions and services for Vietnamese family caregivers caring for their loved ones with dementia.

Currently, there are no social work services available, as well as no social workers working at the NGH. The NGH director board acknowledged the pressing needs for professional social work services to better support patients with dementia and their family caregivers. As a result, they also plan to recruit social workers in their hospital. In the future, social workers need to involve in service development and provision in the hospital setting. The services and interventions need to be built upon caregivers' self-concept, resilience, and cultural values.

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*Table 4.1*  
 Characteristics of caregivers and care recipients

Characteristics	Caregiver participant (N = 20)		Care recipients (N = 19)	
	n	Mean (Range)	n	Mean (Range)
Gender				
Male	7		11	
Female	13		8	
Geographic area of residence				
Rural area	7			
Urban area	13			
Educational level				
Primary school	1		5	
Secondary school	4		5	
High school or Vocational school	5		3	
College or higher	10		6	
Job				
Retired	13			
Farmer	3			
Public officer	3			
House-maid	1			
Marital status				
Married	18			
Single/Divorced/Separated	1			
Widowed	1			
Relationship with CR				
Spouse	13			
Daughter	4			
Daughter-in-law	1			
Son	1			
Son-in-law	1			
Number of people in the household		4 (2 – 10)		
Age		61 (34-86)		73 (57 - 88)
Hours of caregiving per day		7 (3-8)		
Estimated years of dementia exposure				5 (1 – 20)
Estimated months of treatment in NGH				30 (1 – 96)

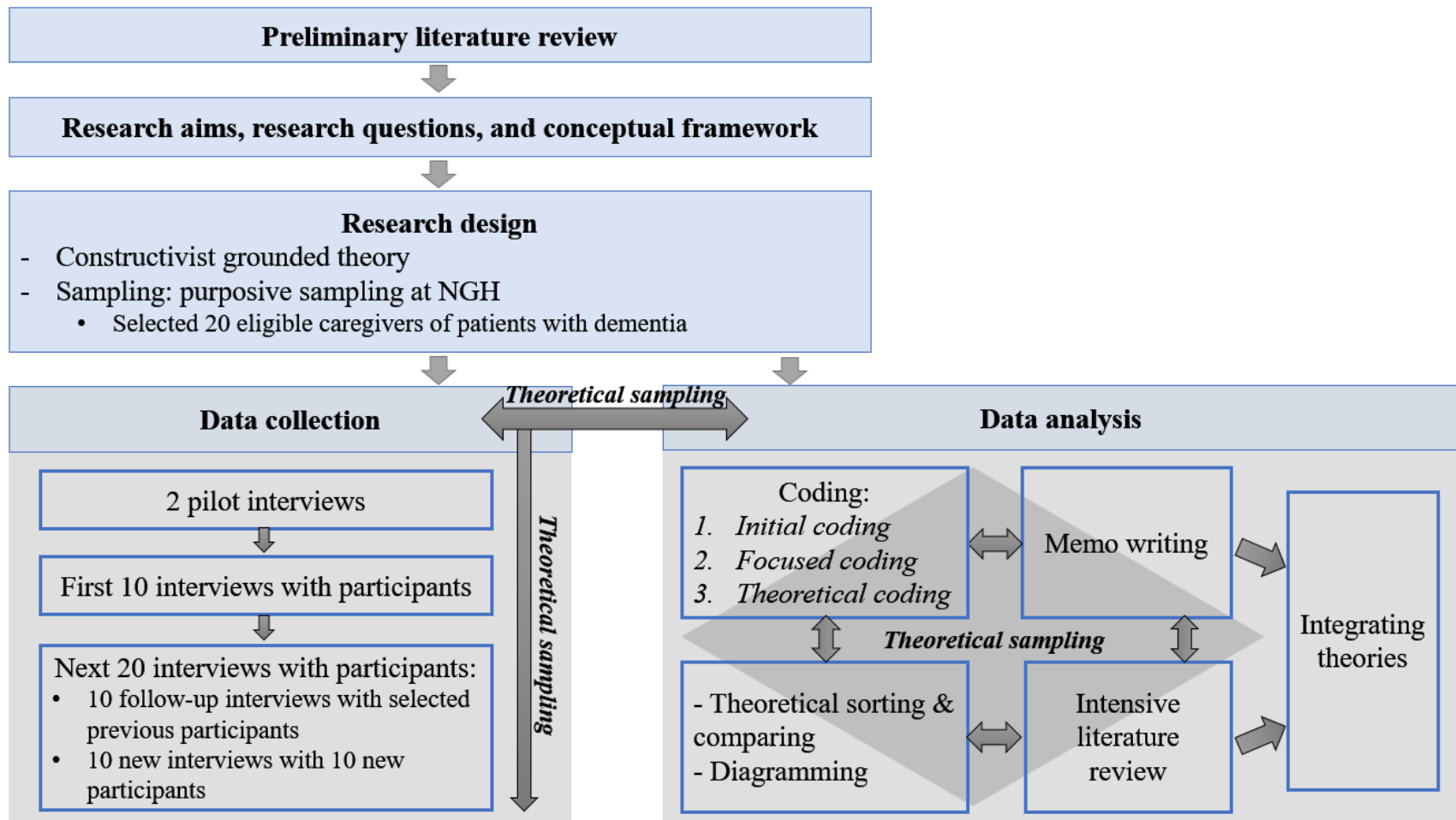


Figure 4.1 Research process flowchart

	Negative spectrum		Positive spectrum
<b>Beliefs/ Perception/ Attitudes</b>	<i>"Have-to-take-it," "What if"</i>	↔	<i>Acceptance, effort/trying, will-power, fate, faith, hope</i>
<b>Emotions</b>	<i><b>Level 1:</b> Worried, tired, pitiful, sad, uncertain, regretful, stressed, guilty, loss of affection, annoyed, disappointed, embarrassed</i> <i><b>Level 2:</b> Exhausted, fear/afraid, stifled, frustrated, angry, sick of it</i> <i><b>Level 3</b> Miserable, shocked, feeling like dying, helpless, overwhelmed, going crazy, desperate, panicked</i>	↔	<i>Feeling better, empathized, loving, assured, content, familiar, enjoyable, happy</i>
<b>Behaviors</b>	<i>Throwing back/comparing to the past, ignoring, crying, comparing to others, cursing, walking away, fighting back</i>	↔	<i>Looking on the positive side, planning for future, finding joys/rewards, sharing feelings with others, focusing on the present, positive downward-comparing, keeping working, self-encouraging, defending dignity/reputation of the care recipient, helping others, self-reflecting</i>

Figure 4.2 Acknowledging the self in caregiving (two spectrums of beliefs/perception/attitudes, emotions, and behaviors)



Figure 4.3 Key beliefs/perception/attitudes, emotions, and behaviors of caregivers in two spectrums.

*Note:* The size of each reaction reflects its frequency reported by participants. The figure illustrates reactions with the frequency reported by participants at least nine times across all transcripts.



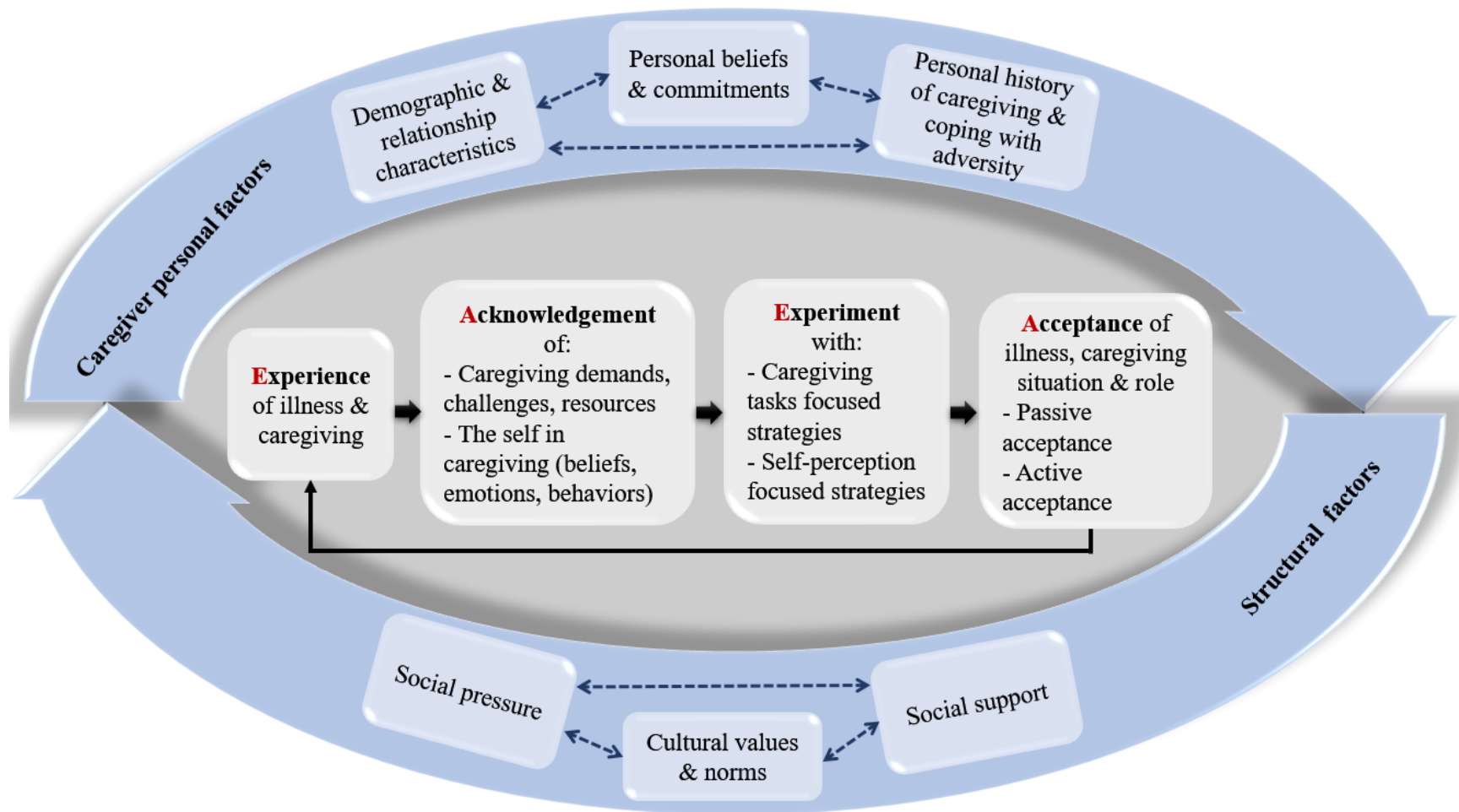


Figure 4.4 The transactional model of the EAEA adjustment process to the caregiving role

## CHAPTER 5

### CONCLUSION

#### 5.1 MAJOR FINDINGS ACROSS THE THREE MANUSCRIPTS

The three papers contribute to portray the experiences of Vietnamese family caregivers in dementia care from different aspects. The study adopted the constructivist grounded theory to collect data from 30 face-to-face, semi-structured interviews with 20 self-identified primary caregivers of older adults with dementia in Vietnam. This first paper explores Vietnamese family caregivers' perception of dementia, caregiving roles, as well as perceived facilitators and barriers to their adjustment to caregiving roles for older adults with dementia. Vietnamese family caregivers held ambiguous perception of dementia. They adopted the mixed explanatory model combining folk and biomedical approaches to explain the nature and causes of dementia. For example, caregivers referred dementia to '*being confused*' as a consequence of the normal aging process, physical health conditions, and psychological distress. They considered caregiving primarily family duty to fulfill their responsibility/obligation based on filial piety (between adult children caregivers) and their affection and gratitude for care recipients (among spousal caregivers). Caregivers revealed facilitators to their caregiving, including care recipients' manageable condition, their own stable physical health, personal beliefs and commitments to caregiving, and social support. Barriers to caregiving consisted of care recipients' problematic behavioral and cognitive symptoms of dementia, caregiving

burdens, caregivers' role demands and conflicts, lack of social support, and social pressure and judgment.

The second paper aims to explore help-seeking perceptions and behavioral patterns of Vietnamese family caregivers of older adults with dementia. The help-seeking process related to caregiving demands emerges from the data as an iterative process of four stages: (1) Disease and caregiving experience; (2) Cognitive appraisal; (3) Action; and (4) Outcomes. Caregivers highly valued independence, autonomy, devotion to family, and self-sacrifices in caregiving. They sought help only when they acknowledged that they could not handle caregiving duty themselves despite their efforts. The common demands/needs which caregivers sought help for included needs for: information seeking for medical decision-making, assistance with interpersonal communication, task sharing in hands-on care, assistance with caregiving emergency (e.g., hospitalization), and self-care. After identifying the demands/needs, they matched them with feasibly formal (e.g., hospital) and informal sources (e.g., family, neighbors, Buddhist temples) available on their social network.

The third paper focuses on exploring the psychological process through which Vietnamese family caregivers adjust to their roles as caregivers of older adults with dementia. The transactional model of the core adjustment process, that emerged from the data, consists of four stages (Experience, Acknowledgement, Experiment, and Acceptance) to the caregiving role (EAEA). Acceptance was not only an ultimate goal, but also a cognitive and psychological journey evolving over time. Caregiver personal factors (demographic and relationship characteristics with care recipients; personal beliefs and commitments in caregiving; and personal history of caregiving and coping

with past adversity) and structural factors (cultural values and norms; social support; and social pressure) interacted with each other and combined to impact the psychological adjustment process of Vietnamese family caregivers.

In conclusion, these three papers provide an overview of caregiving experiences of Vietnamese family caregivers, who were associated with the hospital, in their specific sociocultural context. Connecting the three papers, two key results emerge from the whole study. First, the adjustment process of Vietnamese family caregivers to their caregiving role in dementia care for their loved ones reflects both their traditional values rooted in their culture and their changing sociocultural contexts. Traditional values, such as familism-based responsibility, filial piety, affection and gratitude, significantly shaped family caregivers' perception of caregiving and their adjustment to the role. On the other hand, under the rapid changing context with Western influences, Vietnamese family caregivers adopted new perspectives which modified their perception of caregiving and redirected their adjustment process. For example, participants in the study revealed their open mind to the option of nursing home for their loved ones. This result is unique from existing literature on Vietnamese and Vietnamese immigrants who take care of their older relatives.

Second, all three papers emphasize the importance of the internal psychological factors in shaping the adjustment process of Vietnamese family caregivers to the caregiving role for their relatives with dementia. Results across all three papers reveal that adjustment is a psychological process which is significantly shaped by individual mindset and inner strengths. The adjustment process of family caregivers is a journey in which they learn to accept the reality as it is and respond with active action plans based

on grounded hope. Caregiver resilience plays a more pivotal role than other external factor, such as their socioeconomic status, in guiding them in their adjustment and coping with adversities emerging from caregiving situation.

## **5.2 LIMITATIONS**

Although this study has multiple contributions to the literature on Vietnamese family caregivers in dementia care, it has limitations. First, the study has a relatively small sample size (20 family caregivers). The sample is also homogenous with self-identified primary caregivers from the same Dementia Program at the NGH in Hanoi, the capital city of Vietnam. The sample is more likely knowledgeable in dementia than most of other caregivers in community who did not take their relatives to the hospital for dementia diagnosis and treatment. Besides, as the NGH was located in Northern Vietnam, the sample recruited from this setting shared typical Northern culture. Caregivers from other regions may experience different cultural mechanism in their caregiving. However, this sample size and homogenous characteristics of participants in this study are considered appropriate for a grounded theory study (Guest et al., 2006).

Second, this study faces a challenge in meaning transfer stemming from language translation. While the data collection and analysis were conducted in native Vietnamese language, the result synthesis was conducted in English. During the synthesis process, some specific terms, phrases, and proverbs were challenging to convey fully from Vietnamese to English due to cultural differences. On the other hand, conducting data analysis in the original language helps guarantee the cultural and linguistic authenticity in the meaning transfer of the data (Haidar, 2013; Shibusawa & Lukens, 2004).

Furthermore, validity checking conducted by the two Vietnamese American committee members help address the validity threat to data analysis and synthesis.

Third, the rapport built between the researcher and the participants, as well as the *'therapeutic effect'* of the interviews might influence their adjustment process to some extent (Morecroft, Cantrill, & Tully, 2004). Several caregivers shared that they *'felt better'* after the interviews because the researcher listened to them. Specifically, a female long-term caregiver was interviewed in total three times over the period of six months to examine the changes in her cognitive and behavior adaption. In the first interview, she reported high risks of depression and self-destruction thoughts and extremely negative emotions, such as depressed and feeling like dying. Following the agenda approved by the USC's IRB, after the first interview, the researcher referred her to a mental health service to address her mental health problem. She reported an improvement in her physical and mental health after receiving the treatment. Besides, she emphasized the lack of understanding, empathy, and emotional support from her family members as her biggest stressors in her caregiving. She commented on the effect of the interviews as a channel for her to be open and express her feelings freely. Within six months, this caregiver showed significant progress toward acceptance of her situations. The interviewing effect and the rapport between the researcher and the caregiver possibly play a part in her adjustment process. Therefore, the results of the study also need to take into consideration of this effect.

### **5.3 DISCUSSION**

The adjustment process through which Vietnamese family caregivers go through to adapt to their caregiving role in their dementia care is a complex psychological

process. To understand this process, it is important to investigate different aspects of caregiving experiences, such as caregivers' perceptions of dementia, caregiving, help-seeking, and coping. In addition, it is critical to investigate these aspects of caregiving experiences in caregivers' specific sociocultural contexts. Addressing these demands, the three papers contribute to the literature complex experiences of Vietnamese family caregivers in dementia care by focusing on the three different aspects. The first paper reveals their perception of dementia, caregiving roles, as well as perceived facilitators and barriers to their adjustment to the caregiving role for older adults with dementia. The second paper reports their help-seeking perceptions and behavioral patterns in providing care for relatives with dementia. The third paper provides a profound understanding of the complex psychological process through which Vietnamese family caregivers adjust to their roles as primary caregivers for their loved ones with dementia. The three papers are interconnected, yet, stand out independently.

The self-concept, self-identity, and self-acceptance, as well as the roles of cultural values emerge as the two greatest contributions across the three papers to the understanding of Vietnamese family caregivers' experiences. First, the three papers emphasize the role of the self-concept and self-identity in shaping caregivers' journey with dementia in their daily life. Self-concept and self-identity in caregiving refers to caregivers' acknowledgement of their beliefs, emotions, and behavioral reactions swinging between the negative and positive spectrums. This study argues that dementia care, especially long-term care, may traumatize Vietnamese family caregivers. Given this challenging situation, caregivers' self-acceptance significantly shapes their help-seeking, coping strategies, and adjustment outcomes, such as finding peace of mind. Similar

results are also found among dementia family caregivers and trauma survivors in the Western contexts (Aneshensel et al., 1995; Comer, 2015; Feldman & Kravetz, 2015).

Second, Vietnamese family caregivers' self-concept is embedded in their specific sociocultural context. Vietnamese people show unique religious and spiritual beliefs based on multiple strands of religions. Confucianism and Buddhism are not only perceived as religions, but as a way of life to Vietnamese people. As a result, the key values of familism, filial piety between children and parents, and affection and gratitude between husband and wife, as well as karma, compassion, good deed sowing and reaping, all contribute to shaping Vietnamese family caregivers' perception of caregiving and their psychological adjustment process. Similar results found in Vietnamese immigrants in the U.S. and Australia (Braun et al., 1996; Hinton et al., 2008; Liu et al., 2008; Meyer et al., 2015; Miyawaki, 2015; Truong, 2015; Yeo et al., 2002) emphasize the deep influence and transferring of culture across contexts.

Taken together, the study results across the three papers reflect the culturally unique and universal experiences of dementia caregiving. The study results do not only contribute to the literature on Vietnamese family caregivers, but also provide new ideas on the contributions of self-concept, self-identity, and self-acceptance to understand psychological adjustment processes of family caregivers in broader contexts, as well as of people living with traumas.

#### **5.4 RECOMMENDATIONS FOR FUTURE RESEARCH AND/OR PRACTICE**

The results reported in the three papers call for future studies to extend knowledge of Vietnamese family caregivers in dementia care in their changing sociocultural context. To be specific, more studies are needed to replicate and examine the results found in the



three papers regarding Vietnamese family caregivers' perceptions of dementia, caregiving, facilitators and barriers to caregiving, help-seeking, and adjustment process. Particularly, the results from these three papers call for future studies to deepen the understanding of resilience and inner strengths of Vietnamese family caregivers to adjust to the hardship of caregiving situation. Future studies should be conducted with larger sample sizes and more diverse participants and settings in Vietnam including those caregivers who have not had contact with the formal medical care system.

Moreover, the study results yield practical implications for supporting Vietnamese family caregivers for older adults with dementia. The study results inform the development of interventions and services, especially culturally competent intervention and services for dementia family caregivers. Newly developed interventions and services for Vietnamese family caregivers should be built upon their resilience and cultural values with a consideration of the changing context in the Vietnamese society. The study results also contribute to policy advocacy targeting family caregivers in the Vietnamese social welfare system. Until now, there is no policy or social service for family caregivers in the formal social service system in the country. Along with the rise of social work profession in Vietnam, social work is expected to contribute to the area of older adult care and family caregiver support. This study, therefore, contributes to the development of the social work scholarship targeting these underserved populations.

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## APPENDIX A

### INTERVIEW QUESTIONS

#### **Initial open-ended questions (Grand tour questions)**

- What are three words to describe your experience caring for your relative?
- Why did you choose these words?

#### **Intermediate questions**

- Why did you take your relative to the hospital for the examination? Or: What did you first notice that made you think about bringing your relative to the hospital? What did you think it was? What terms did you use to describe those problems/symptoms?
- What did you learn about the diagnosis result? What terms did the doctor use to describe your relative's problem (e.g., memory problems and other symptoms, such as apathy, depression, etc.)? Had you ever heard about those terms before?
- What did you think after learning about the problems [dementia/equivalent term which the participant uses] of your relative from the doctor? What did you do after learning about the diagnosis results?
- What are your daily care routines? Or: Could you describe a usual day of you and your relative (with dementia)?
- Was there anyone help you with these care routines? If yes, who were they? What and when did they often help you with care activities?

- What is the division of labor in your family? What changes do you think would make it better?
- What do you think about the relationship between providing care for the relative with dementia and morality in your community?
- Is there any support in your community that helps you in caring for your relative? If yes, could you please tell me more about them? Who/What provide the biggest/most important support? Why?
- Is there any aspect in your community that makes it difficult for you to care for your relative? If yes, could you please tell more about them? What are the biggest/most important challenges? Why? Have you ever asked someone (your family, friends, neighbors, etc.) for help to care for your relative? What did you ask for help? What were the results? Were you satisfied with them?
- Do you know about any organization, agency, clinic, or professional in your community that you can ask for help regarding your care for your relative? If yes, have you ever tried to ask any of them for help? What were the results? Were you satisfied with them?
- Have you noticed any change in your relative's symptoms until now? If yes, did you change your care routines due to your relative's symptom changes?
- What do you think about the future, such as any concern about your relative? Did you plan anything to deal with that?
- How does caregiving impact your personal life, such as your work, relationships with your spouse, friends, and other? Is there any difference in spending time for



yourself, family, friends, and other activities between before and after providing care for your relative?

- Did you do anything to take care of yourself along with taking care of your relative? If yes, what did you do?
- Have you ever noticed any change in your family dynamic since your relative started exposing [dementia] problems? If yes, how did your family dynamics change? What did you do to adapt to those changes?
- What does providing care to the relative with dementia mean to you?
- How do you do to get through the day? What help you with your caregiving duty?
- How confident you are with providing care for your relative? Do you feel like you are doing a good job? Why?
- What are the hardest parts of your role as a caregiver? Why?
- What are the most positive aspects of caregiving? Why?

### **Demographic questions**

- Caregiver characteristics: age, gender, educational level, job, religion, relationship with the care recipient, residential characteristic (co-reside with the care recipient or not), care duration, average care hours per day or week.
- Care recipient characteristics: age, gender, educational level, health condition (e.g., type of dementia, course, and severity of the illness).

### **Ending questions**

- Is there anything else you think I should know to understand your caregiving experience better?
- Is there anything you would like to ask me?